

Negative Symptoms in First-Episode Psychosis: A Mixed Methods Investigation



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ABSTRACT

Negative symptoms – reductions in expression, motivation, pleasure and sociability – are observed across the spectrum of functional psychoses. They have been identified as a significant predictor of poor outcomes following first-episode psychosis and are a treatment priority for individuals with lived-experience of psychosis. However, the mechanisms underlying negative symptoms remain poorly understood. This thesis aims to contribute to our understanding of negative symptoms in the early phase of psychosis using a mixed methods approach.

Participants in the EDEN study ($n = 1006$) were followed up for 12 months following acceptance into UK Early Intervention in Psychosis services. Negative symptom severity data were modelled using latent class growth analysis, allowing latent classes comprising individuals with similar patterns of change in negative symptoms severity over time to be identified. Predictors of latent class membership were ascertained and the relationship between negative symptom trajectories and concurrent social recovery explored. Subsequently, transcripts of qualitative interviews conducted with a subsample ($n = 24$) of the cohort were analysed thematically. Comparisons were made between the accounts of members of the identified latent classes. Experiences and personal understandings of negative symptoms, psychosis, treatment and recovery were explored, providing insights into potential mechanisms underlying negative symptoms and their relationship with social recovery.

The quantitative and qualitative findings were integrated and interpreted in relation to existing research and theory. Together they informed the development of a conceptual model of negative symptoms and their relationship with poor social recovery following first-episode psychosis. The model suggests that active psychological processes may be important to negative symptoms and their contribution to poor social recovery. It is proposed that offering tailored psychosocial interventions at the earliest stage of disorder – after the onset of non-specific negative symptoms but before the emergence of attenuated positive symptoms – may be warranted to improve outcomes following psychosis onset.

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LIST OF ABBREVIATIONS

AIC	Akaike's Information Criterion
ANOVA	Analysis of Variance
ASR	Adjusted Standardised Residuals
BIC	Bayesian Information Criterion
BLRT	Bootstrap Likelihood Ratio Test
BNSS	Brief Negative Symptom Scale
BPRS	Brief Psychiatric Rating Scale
CAINS	Clinical Assessment Interview for Negative Symptoms
CBT	Cognitive Behavioural Therapy
CBTp	Cognitive Behavioural Therapy for Psychosis
CBTn	Cognitive Behavioural Therapy for Negative Symptoms
CDSS	Calgary Depression Scale
CFA	Confirmatory Factor Analysis
CFI	Comparative Fit Index
CNEIT	Central Norfolk Early Intervention Team
CPN	Community Psychiatric Nurse
CRT	Cognitive Remediation Therapy
DSM	Diagnostic and Statistical Manual of Mental Disorders
DUP	Duration of Untreated Psychosis
EFA	Exploratory Factor Analysis
EIP	Early Intervention in Psychosis
ESEM	Exploratory Structural Equation Modelling
ESRC	Economic and Social Research Council
FEP	First-Episode Psychosis
FIML	Full Information Maximum Likelihood
GMM	Growth Mixture Modelling

ICD	International Classification of Diseases
LCGA	Latent Class Growth Analysis
LGM	Latent Growth Modelling
LMR-LRT	Lo–Mendell–Rubin Likelihood Ratio Test
MAR	Missing at Random
MASS	Motor-Affective-Social Scale
MPS-SR	Motivation and Pleasure Scale Self-Report
NICE	National Institute for Health and Care Excellence
PANSS	Positive and Negative Syndrome Scale
PAS	Premorbid Adjustment Scale
QLS	Quality of Life Scale
QSA	Qualitative Secondary Data Analysis
RCT	Randomised Controlled Trial
RMSEA	Root Mean Square Error of Approximation
SANS	Scale for the Assessment of Negative Symptoms
SNS	Self-Evaluation of Negative Symptoms
TLI	Tucker-Lewis Index
TUS	Time Use Survey

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PREFACE

This thesis is submitted to the University of East Anglia for the degree of Doctor of Philosophy. I declare that this thesis presents my original work, that no part has been previously accepted and presented for the award of any degree or diploma from any university, and that, to the best of my knowledge, no material previously published or written by any other person is included, except where due acknowledgment is given.

The thesis is 78,408 words and 275 pages in length, inclusive of legends, footnotes and references.

Parts of this work have been presented in the following publications and conference contributions:

Gee, B., Hodgekins, J., Lavis, A., Notley, C., Birchwood, M., Everard, L., Freemantle, N., Amos, T., Jones, P. B., Marshall, M., Sharma, V., Singh, S., Smith, J., McCrone, P., Fowler, D. (Submitted) Lived-experiences of negative symptoms in first-episode psychosis: a qualitative secondary analysis.

Gee, B., Hodgekins, J., Fowler, D., Marshall, M., Everard, L., Lester, H., Jones, P. B., Amos, T. Singh, S., Sharma, V., Freemantle, N., Birchwood, M. (2016) The Course of Negative Symptoms in First Episode Psychosis and the Relationship with Social Recovery. *Schizophrenia Research*, 174, 165-71

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Gee, B., Hodgekins, J., Fowler, D., Notley, C., Lavis, A. (2015) How Do Negative Symptoms Impact Upon the Experience of First Episode Psychosis? (Conference contribution) 19th International Congress of the International Society for Psychological and Social Approaches to Psychosis, New York City, USA

French, P., Clarke, T., **Gee, B.**, Hodgekins, J., Fowler, D. (2015) Social Recovery across the Course of Psychosis: A CBT Approach, (Conference contribution) 19th International Congress of the International Society for Psychological and Social Approaches to Psychosis, New York City, USA

Hodgekins, J., **Gee, B.**, Birchwood, M., Marshall, M., Singh, S., Fowler, D. (2014) Trajectories of negative symptoms following a first episode of psychosis and implications for social and functional recovery. In: Early Intervention in Psychiatry. pp. 23 (Conference contribution)

I declare that the work presented in this thesis is my own. The co-authors of the publications and conference contributions resulting from it were members of the PhD supervisory team and/or key investigators in the EDEN research programme. The EDEN team kindly permitted the use of the EDEN datasets for the purposes of the research described in this thesis and provided valuable guidance and feedback during the research process.

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Since embarking on my doctoral studies I have heard many a PhD horror story. Such stories, while their details vary, tend to share a moral: the successful completion of a PhD is a team endeavour, not a solo pursuit. My own PhD experience has been remarkably horror-free; for this I have many people to thank.

I would first like to thank my supervisors: Dr Jo Hodgekins, Prof David Fowler and Dr Caitlin Notley. Jo, I am incredibly grateful for your guidance and encouragement, your trust in my abilities, belief in the value of the research, and especially for your dedication in continuing to offer feedback and advice whilst on maternity leave. David, thank you for encouraging me to peruse a PhD in the first place and for sharing your experience, knowledge and enthusiasm: this thesis would likely have been twice as long and half the quality without your input. Caitlin, your support, feedback, and guidance on all things qualitative have been invaluable. Thank you so much for stepping in as primary supervisor during Jo's leave.

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I am incredibly lucky to have an unfailing supportive and generally wonderful family and lovely friends. Thank you for encouraging and supporting me in all I do. Very special thanks to Sameer for providing a multitude of support, both emotional and practical, during my PhD. I could have completed this thesis without you (the feminist in me won't allow me to say otherwise), but I am very glad I didn't have to. I love you.

Finally, I would like to thank all those who participated in the research. I am immensely grateful to every single person – both those who I had the privilege of meeting, and the many who I will never meet – who selflessly gave up their time and shared deeply personal aspects of their lives for the sake of the research. Thank you.

PART ONE

Introduction

Chapter One – Background

1.1. GENERAL OVERVIEW

Negative symptoms are a common and disabling feature of schizophrenia and other psychotic disorders which often go untreated (Kirkpatrick, Fenton, Carpenter, & Marder, 2006) despite being a treatment priority for service-users (Sterk, Winter van Rossum, Muis, & de Haan, 2013). Negative symptoms are characterised by reductions in functioning in five key domains: expression, speech, motivation, pleasurable emotions and social interest. These deficits are referred to in the literature as affective blunting, alogia, avolition, anhedonia and asociality respectively.

The research described in this thesis concerns negative symptoms as they manifest during the first psychotic episode and its aftermath. Negative symptoms were previously considered residual symptoms of chronic schizophrenia (Pfohl & Winokur, 1982; J. S. Strauss, Carpenter, & Bartko, 1974) and the majority of early negative symptoms research focused on this population (Montague, Tantam, Newby, Thomas, & Ring, 1989). However, it is now clear that negative symptoms are not specific to those who meet diagnostic criteria for schizophrenia, nor to chronic presentations. Negative symptoms are observed across the spectrum of functional psychotic disorders (Lyne et al., 2012; Macmillan et al., 2007) and typically emerge early in the course of psychosis, often during the prodromal phase (Häfner, Löffler, Maurer, Hambrecht, & an der Heiden, 1999; Yung & McGorry, 1996).

This thesis will advocate a biopsychosocial approach to understanding negative symptoms. The literature on negative symptoms has tended to prioritise biological explanations (Tarrier, 2006), with much research effort dedicated to identifying biological correlates of negative symptomatology (Millan, Fone, Steckler, & Horan, 2014). Correspondingly, treatment research in this field has largely focused on identifying pharmacological agents capable of ameliorating negative symptoms (Davis, Horan, & Marder, 2014; Marder, Daniel, Alphs, Awad, & Keefe, 2011).

Unfortunately, this approach has been slow to yield results; the mechanisms underlying negative symptoms remain poorly understood and effective pharmacological treatments for negative symptoms have proved elusive (Erhart, Marder, & Carpenter, 2006; Foussias, Siddiqui, Fervaha, Agid, & Remington, 2015).

A growing body of evidence suggests a role for psychological and social factors in the maintenance of negative symptoms, sparking interest in the use of psychosocial interventions to treat negative symptoms (Kern, Glynn, Horan, & Marder, 2009). Early research suggested that cognitive behavioural therapy for psychosis may be an effective treatment for negative symptoms (Wykes, Steel, Everitt, & Tarrier, 2008). However, a recent meta-analysis found that more recent, methodologically rigorous research does not support this conclusion (Velthorst et al., 2015). Interventions specifically designed to target the psychological underpinnings of negative symptoms are likely to be required in order to adequately treat these debilitating symptoms. Improved understanding of the psychosocial factors relevant to negative symptoms will be important in facilitating the development of interventions capable of meeting this aim. This thesis aspires to contribute to such improvements in understanding.

This opening chapter aims to situate the research that follows within the wider literature. The chapter begins by defining psychosis and schizophrenia. Next, an overview of the history of negative symptoms is provided and contemporary definitions and measurement of negative symptoms are discussed. Existing theoretical models of negative symptoms are then outlined and currently available treatment options reviewed. Next, the rationale for early intervention in psychosis is set out and an argument for the importance of focusing on negative symptoms within the context of early psychosis presented. Finally, the rationale for the current research is summarised and the overarching research design and structure of the thesis are outlined.

1.2. PSYCHOSIS AND SCHIZOPHRENIA

Experiences sometimes thought of as indicative of psychosis include seeing, hearing, smelling, tasting or feeling things that other people do not, believing things that others find strange, and speaking in ways that others find hard to follow (The British Psychological Society, 2014). Many of those who have these kinds of experiences are not distressed by them and never come into contact with mental health services (Johns et al., 2014; Peters, Day, Mckenna, & Orbach, 1999). However, where these experiences are distressing or impact significantly on functioning, those experiencing them may seek professional help, or others may seek it on their behalf. When individuals come into contact with mental health services, these experiences may come to be thought of as symptoms of a disorder and termed 'hallucinations', 'delusions' and 'thought disorder' respectively. Hallucinations, delusions and thought disorder comprise the category of 'psychotic symptoms'.

Psychotic symptoms are not specific to any one diagnostic category but occur across a range of psychiatric disorders (as well as many organic disorders (Cummings, 1985)). They are characteristic features of the schizophrenia-spectrum diagnoses including schizophrenia, schizoaffective, schizotypal and delusional disorders (World Health Organisation, 1992), and also feature in the diagnostic criteria for non-schizophrenia spectrum disorders including bipolar disorder and unipolar depression (ibid.). Schizophrenia is the most common psychotic disorder, estimated to effect more than 21 million people worldwide (World Health Organisation, 2016). As such, it is often considered prototypical of psychotic disorders (Barnhill et al., 2014; Freudenreich, 2016).

The most recent fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5; American Psychiatric Association, 2013) lists five symptom domains characteristic of schizophrenia: (1) delusions, (2) hallucinations, (3) disorganized speech, (4) grossly disorganized or catatonic behaviour, and (5) negative symptoms. Negative symptoms are defined within the DSM-5 as 'diminished emotional expression' (understood to incorporate blunted affect and alogia) and 'avolition' (understood to encompass amotivation, asociality and

anhedonia) (Millan et al., 2014). In order to meet criteria for schizophrenia, an individual must present with symptoms from at least two of the five domains, at least one of which should be (1), (2) or (3). Thus the DSM-5 considers negative symptoms to be neither necessary nor sufficient for a diagnosis of schizophrenia. However, the emphasis placed on negative symptoms in the diagnosis of schizophrenia has varied considerably over time according to prevailing views of the nature of the disorder (Tandon et al., 2013).

1.3. NEGATIVE SYMPTOMS: A BRIEF HISTORY

1.3.1. Negative Symptoms and Schizophrenia

Deficits in line with those now classified as negative symptoms have been considered important features of schizophrenia since the earliest descriptions of the disorder. Kraepelin, in his description of dementia praecox (1971/1919), describes weakening of ‘the main springs of volition’ resulting in ‘emotional dullness, failure of mental activities, loss of mastery over volition, of endeavour, and of ability for independent action’ as the core of the disorder (Zec, 1995). Similarly, Bleuler (1950/1911) considered ambivalence, abnormalities of affect, and disturbance of volition to be among the fundamental symptoms – those present in every case and during every period of illness – of the ‘group of schizophrenias’ (Heckers, 2011). This early emphasis on negative symptoms within descriptions of schizophrenia is reflected in the first two versions of the DSM which placed substantial emphasis on negative symptoms in the diagnosis of schizophrenia (Tandon et al., 2013).

The DSM-I (American Psychiatric Association, 1952) listed nine subtypes of schizophrenia, the first of which was described as being characterised by “reduction in external attachments and interests and by impoverishment of human relationships ... usually accompanied by apathy and indifference but rarely by conspicuous delusions or hallucinations” (p. 26). This ‘simple’ subtype of schizophrenia, characterised predominantly by what would come to be known as negative symptoms, was removed in DSM-III, reintroduced in DSM-IV, and removed again

in DSM-5 (Fortea et al., 2016). The diagnosis of ‘simple schizophrenia’ is retained in the most recent *International Classification of Diseases* (ICD-10; World Health Organisation, 1992), thus preserving the possibility of making a diagnosis of schizophrenia on the basis of negative symptoms alone. However, simple schizophrenia is an extremely uncommon diagnosis even where it continues to be employed (Fortea et al., 2016; Serra-Mestres et al., 2000); negative symptoms are rarely identified clinically in those who have not also presented with psychotic symptoms.

The term ‘negative symptoms’ has its origins in neurology (Pearce, 2004). Early epilepsy researchers drew a contrast between symptoms involving a loss of normal functioning (such as paralysis and loss of sensation), which they termed ‘negative’, and symptoms involving an excess of functioning (such as abnormal movements and hallucinations), which they termed ‘positive’. Controversial psychiatrist Snezhnevsky (1904–1987) was the first to apply this terminology to the symptoms of schizophrenia (Malaspina et al., 2014). Negative symptoms were a decisive feature of Snezhnevsky’s ‘sluggish schizophrenia’ diagnosis, since discredited due to its role in the wrongful detention of political dissidents during the Soviet era (Smulevich, 1989).

Snezhnevsky’s typology of schizophrenia symptoms was developed and refined by Strauss et al. (1974) who delineated three symptom classes: ‘positive symptoms’, ‘negative symptoms’ and ‘disorders of personal relationships’. They defined positive symptoms as ‘disorders of content of thought and perception, certain types of form of thought (e.g., distractibility) and certain behaviours (e.g., catatonic motor disorders)’. Negative symptoms were defined as ‘blunting of affect, apathy, and certain kinds of formal thought disorder, such as blocking’. Disorders of personal relationships were described by Strauss et al. as akin to Meehl’s (1962) concept of ‘interpersonal aversiveness’, encompassing social fear, distrust and expectation of rejection.

Strauss et al. (1974) suggested that these symptom clusters might reflect distinct pathological processes within the schizophrenia syndrome. This suggestion was enthusiastically embraced by researchers attempting to explain marked heterogeneity in the clinical presentation, course and outcome of schizophrenia. Crow (1980; 1985) proposed that schizophrenia could be divided into two distinct syndromes: 'Type I' schizophrenia, characterised by a predominance of positive symptoms and an acute course, and 'Type II' schizophrenia, characterised by a predominance of negative symptoms and a chronic course. He suggested that Type I schizophrenia might have a neurochemical origin responsive to antipsychotic medication whereas Type II schizophrenia was more likely to be the result of structural brain changes and therefore invulnerable to pharmacological interventions.

Also concerned with delineating distinct subtypes of schizophrenia, and noting negative symptoms' lack of specificity, Carpenter & Kirkpatrick (1988) introduced a distinction between 'primary' and 'secondary' negative symptoms. Primary negative symptoms are defined as those negative symptoms stemming directly from the neurobiological pathology presumed to underlie schizophrenia. Secondary negative symptoms are those negative symptoms that can be explained by other aspects of the disorder, for instance responses to positive symptoms, depression, medication or environmental under-stimulation. Drawing on this distinction, Carpenter et al. (1988) suggested a subtype of schizophrenia characterised by the presence of negative symptoms that are both primary and enduring (present for at least 12 consecutive months) which they designated the 'deficit syndrome'. They have argued that the deficit syndrome may represent a separate 'disease' within the schizophrenia syndrome (Kirkpatrick, Buchanan, Ross, & Carpenter, 2001).

Following the 1980s 'renaissance' of interest in negative symptoms (Andreasen, 1982), negative symptoms research has grown considerably (Figure 1.1). Much of this research has been stimulated by the association between negative symptoms and a range of adverse outcomes (Stahl & Buckley, 2007). More recently, recognition of the failure of the new generation of atypical antipsychotics to offer appreciable benefits for negative symptoms (Murphy, Chung, Park, & McGorry, 2006) has led to

a renewed focus on negative symptoms as a therapeutic target (Erhart et al., 2006; Kirkpatrick et al., 2006).

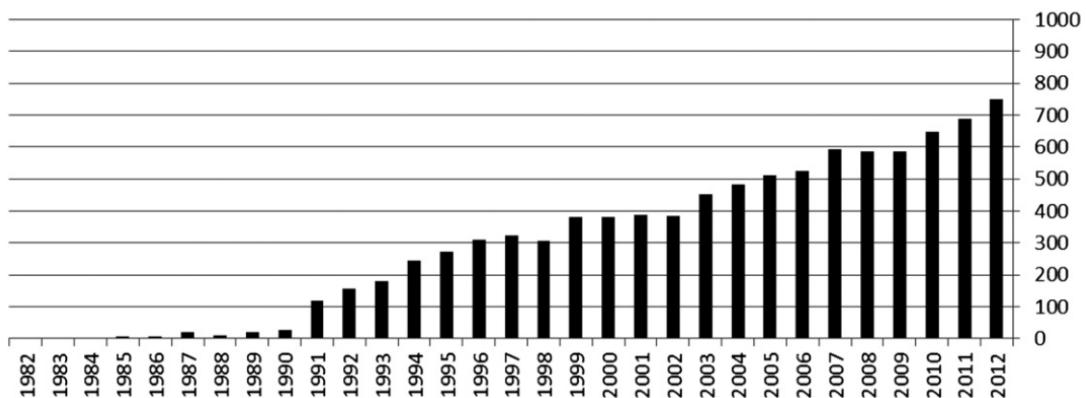


Figure 1.1. 'Citations per year using the terms "negative symptoms" and "schizophrenia" reproduced from Cohen, Mitchell, & Elvevåg (2014).

1.3.2. Negative Symptoms Beyond Schizophrenia

While the negative symptom construct was initially developed in the context of the study of schizophrenia, its trans-diagnostic relevance has become increasingly recognised (Foussias, Agid, Fervaha, & Remington, 2014). The occurrence of negative symptoms in affective psychoses has been less widely studied than in schizophrenia-spectrum disorders and some have supposed negative symptoms to be specific to non-affective psychoses (Montague et al., 1989; Reddy, Mukherjee, & Schnur, 1992). However, more recent evidence suggests that negative symptoms do occur in individuals diagnosed with affective psychoses but less commonly than in those diagnosed with non-affective psychoses (Lyne et al., 2012). Further, negative symptoms have been found to be a feature of clinical depression (Gerbaldo et al., 1995) as well as neurological disorders such as Parkinson's disease, Alzheimer's disease, Huntingdon's disease, frontal-lobe dementia and traumatic brain injury (Foussias et al., 2014; Winograd-Gurvich, Fitzgerald, Georgiou-Karistianis, Bradshaw, & White, 2006), and are observed in young people at high risk of psychosis (Azar et al., 2016; Yung et al., 2005).

1.4. DEFINING AND MEASURING NEGATIVE SYMPTOMS

1.4.1. Clinical Rating Scales for Negative Symptom Measurement

The scientific measurement of negative symptoms commenced with the publication of the Brief Psychiatric Rating Scale (BPRS; Overall & Gorham, 1962). The BPRS includes just two negative symptom items: 'emotional withdrawal' and 'blunted affect'. This was followed in the 1980s by the development of a number of instruments measuring negative symptoms more broadly. Of these, the Scale for the Assessment of Negative Symptoms (SANS; Andreasen, 1982) and the negative subscale of the Positive and Negative Syndrome Scale (PANSS; Kay, Fiszbein, & Opler, 1987) have proved most popular and enduring (Marder & Kirkpatrick, 2014). Both measures require the researcher to rate aspects of the participant's behaviour on a series of anchored severity scales using information obtained via a clinical interview and reports of caregivers and/or family.

Whilst there is significant overlap in the content of these older rating scales, there is also some divergence. Fenton & McGlashan (1992) compared the content of eight published negative symptom rating scales and found that only blunted affect was included by all instruments. In an attempt to counter this lack of consistency, participants in the National Institute of Mental Health's Consensus Development Conference on Negative Symptoms published a consensus statement (Kirkpatrick et al., 2006) stating that they considered blunted affect, alogia, avolition, asociality and anhedonia to fall within the domain of the negative symptom construct. This definition of negative symptoms has been widely embraced.

The authors of the consensus statement recommended the use of the SANS and PANSS to measure negative symptoms (*ibid.*). However, they also recognised the limitations of these measures, including the inclusion of items not considered to belong to the negative symptom construct (such as those related to cognitive impairments and disorganisation) and the reliance on behavioural observations to measure ostensibly experiential phenomena such as anhedonia. As such, the

consensus statement advocated the development of improved instruments to measure negative symptoms. Since this call, three new clinical rating scales have been developed: the Clinical Assessment Interview for Negative Symptoms (CAINS; Kring, Gur, Blanchard, Horan, & Reise, 2013), the Brief Negative Symptom Scale (BNSS; G. P. Strauss et al., 2012), and the Motor-Affective-Social Scale (MASS; Trémeau et al., 2008). The content of the SANS, PANSS, CAINS, BNSS and MASS are summarised alongside each other for comparison in Table 1.1.

Table 1.1. Content of first- and second-generation clinical rating scales for the assessment of negative symptoms.

SANS	PANSS (Negative subscale)	CAINS	BNSS	MASS
Affective flattening	Blunted affect	Expression: Facial and gestures	Blunted affect	Spontaneous smiles Coverbal hand gestures
Alogia	Poor rapport Lack of spontaneity/ flow of conversation	Expression: Vocal prosody and speech	Alogia	Number of questions asked by interviewer Reported verbal interaction
Avolition- Apathy	Emotional withdrawal	Motivation/ pleasure: recreation, vocational	Avolition	Grooming/ hygiene
Anhedonia- Asociality	Passive social withdrawal	Motivation/ pleasure: social	Anhedonia Asociality	Participation in groups/ activities
Attentional impairment	Difficulty in abstract thinking Stereotyped thinking		Distress	
SANS = Scale for the Assessment of Negative Symptoms; PANSS = Positive and Negative Syndrome Scale; CAINS = Clinical Assessment Interview for Negative Symptoms; BNSS = Brief Negative Symptom Scale; MASS = Motor-Affective-Social Scale				

The second-generation clinical rating scales improve on older scales by including only item content in line with modern conceptions of negative symptoms, omitting items measuring attentional impairments, cognitive difficulties or disorganisation. Additionally, the CAI NS and BNSS seek patient reports of reductions in pleasure, sociability and motivation, thus relying less heavily on behavioural observation to gauge the degree of experiential deficits. Conversely, the MASS focuses solely on observable behaviour, operationalising avolition and asociality as staff reports of grooming and hygiene and participation in activities. The MASS's authors exclude anhedonia from the negative symptoms domain on the grounds that, in laboratory conditions, individuals diagnosed with schizophrenia have been found to report as much pleasure in response to pleasurable stimuli as healthy controls. The CAI NS and BNSS account for these findings by distinguishing between consummatory and anticipatory pleasure (see section 1.5.2 for discussion of this distinction).

The MASS's reduction of negative symptoms to certain behaviours was motivated by the authors' desire to create an objective rating method uncontaminated by the rater's subjective global impression. The excellent inter-rater reliability achieved (item level intra-class correlations (ICCs) ranged from 0.87 to 1 (Trémeau et al., 2008)) would suggest that the authors' efforts to limit subjectivity were successful. The inter-rater reliability of the MASS compares favourably to other measures of negative symptoms, including the PANSS negative subscale (ICC = 0.80; Peralta & Cuesta, 1994), SANS (ICC = 0.84; Andreasen, 1982) and CAI NS (ICCs = 0.67-0.94; Kring et al., 2013). However, the construct validity of the MASS is questionable; reduced participation in activity groups could reflect many factors other than asociality, and avolition could manifest in a variety of behavioural changes in addition to reduced grooming and hygiene. Thus there is a trade-off to be made between greater objectivity (and thus reliability) and better construct validity.

1.4.2. Other Paradigms for Negative Symptom Measurement

In addition to the new clinical rating instruments for negative symptoms, a number of objective laboratory measures are emerging. Objective paradigms offer a number of potential benefits over clinical assessments, including limiting the problems of inter-rater reliability, rater-drift, and floor and ceiling effects that often affect clinical rating scales (Foussias et al., 2015). Laboratory measures of blunted affect and alogia include video-based automated analysis of facial expressiveness and expressive movements, as well as acoustic analysis of the rate of speech and vocal prosody (Cohen & Elvevåg, 2015; Cohen, Alpert, Nienow, Dinzeo, & Docherty, 2008; Gard, Kring, Gard, Horan, & Green, 2007). Laboratory measures of anhedonia and avolition include tests of emotional experience in response to stimuli and computer-based measurements of task effort and cost-effort computations (Horan et al., 2015). These new paradigms are still in the early stages of development and their external validity remains unclear. Nonetheless they represent promising future opportunities for more nuanced investigations of the behavioural and motivational constituents of negative symptoms.

There have also been recent efforts to develop self-report measures of negative symptoms. The Motivation and Pleasure Scale Self-Report (MPS-SR; Llerena et al., 2013) is a self-report version of the CAINS developed for use as a screening tool where circumstances preclude the administration of a clinical interview. The initial intention of the MPS-SR's authors was to assess all those negative symptoms covered by the CAINS, however the poor convergent and discriminant validity of the items assessing blunted affect and alogia led to their removal from the final version of the measure (Park et al., 2012). Another self-report measure, the Self-Evaluation of Negative Symptoms (SNS; Dollfus, Mach, & Morello, 2016) provides a more complete assessment of negative symptoms, with items assessing affective blunting and alogia in addition to avolition, anhedonia and asociality. The item content of the SNS was developed from descriptions of the experience of negative symptoms given by individuals diagnosed with schizophrenia during focus groups. The aim was not to design a measure that could serve as a proxy for observer-rated measures, but to

encourage the service-user's perspective on their negative symptoms to be considered a valuable outcome in itself.

Mirroring the poor convergent validity of the items assessing blunted affect and alogia removed from the MPS-SR, SNS items assessing emotional range were found not to correlate significantly with corresponding clinical rating scale items. The authors explain this discrepancy by noting that what is being assessed via observer ratings of blunted affect and alogia – limited expressivity – is distinct from the emotional experience of the participant. The one SNS item that did correlate with observer-rated blunted affect (“It is difficult for people to know how I feel”), suggests that individuals with schizophrenia are able to accurately report reductions in their emotional expression when these are inquired about explicitly.

1.4.3. Negative Symptoms: Unitary or Multidimensional Construct?

Negative symptoms have most often been treated as a unitary construct by researchers, justified by their having consistently emerged as a single factor in studies of schizophrenia symptomatology (Blanchard & Cohen, 2006). However, there is an emerging consensus that they may be better characterised as a multidimensional construct, comprising at least two separable factors (Messinger et al., 2011). A review of factor analytic studies of the SANS found the most commonly identified factor structure to comprise one factor indicated by blunted affect and alogia, and another by apathy, avolition, asociality and anhedonia (Blanchard & Cohen, 2006). These two factors have been referred to as ‘diminished expression’ and ‘withdrawal’ (or sometimes ‘diminished experience’, ‘diminished motivation’, ‘apathy’ or ‘social amotivation’ depending on how this second factor is conceptualised). Studies using other negative symptom measures, including the PANSS (Liemburg et al., 2013), CAINS (Kring et al., 2013) and BNSS (G. P. Strauss et al., 2013a), have also arrived at this two-factor structure (though see Garcia-Portilla et al., 2015).

Strauss et al. (2013b) studied the clinical presentations of individuals given a diagnosis of schizophrenia and identified two subgroups of patients with distinct negative symptom profiles. One subgroup presented with symptoms predominantly from the diminished expression domain, another with predominantly motivational deficits. The two groups differed significantly on measures of functioning, premorbid adjustment, clinical course, deficits in social cognition, sex and ethnicity. Such findings have led some to suggest that these two subdomains of negative symptoms may have distinct aetiologies (Foussias & Remington, 2010) and thus may respond to different treatments (Foussias et al., 2015).

1.5. MODELS OF NEGATIVE SYMPTOMS

Researchers have proposed a number of theoretical models of negative symptoms in a bid to explain the nature and causes of these phenomena. These models can be grouped into three broad categories: neurodevelopmental, neurocognitive and cognitive. This section will outline key models of negative symptoms from each of these categories and the evidence in support of them.

1.5.1. Neurodevelopmental Models of Negative Symptoms

Neurodevelopmental models of negative symptoms propose that these symptoms are a direct manifestation of the neuropathology at the core of schizophrenia. Whilst this theory was implicit in the earliest accounts of schizophrenia, it was first clearly articulated by Crow in his writings on the distinction between Type I and Type II schizophrenia (1980; 1985). Crow hypothesised that negative symptoms are the result of irreversible structural brain changes caused by an unknown pathological process. This theory was a response to early evidence of an association between negative symptoms and increased ventricle size, as well as negative symptoms' lack of response to anti-psychotic medications. Subsequent neuroimaging studies have uncovered associations between negative symptoms and abnormalities in grey and white matter volumes in several regions including the prefrontal cortex, thalamus, precentral cortex and inferior parietal gyrus (Asami et al., 2014). Furthermore, there

is some evidence implicating dysfunctional neural circuitry in negative symptom maintenance – most consistently frontotemporal and frontocorticostriatal circuits (Millan et al., 2014).

Cornblatt et al. (Cornblatt et al., 2003; Lencz, Smith, Auther, Correll, & Cornblatt, 2004) proposed that negative symptoms are the result of underlying brain abnormalities with a significant genetic component, perhaps contributed to by early insults such as viral infection or environmental toxins. They suggest that, prior to the onset of psychosis, this underlying neuropathology manifests as negative-like symptoms and other non-specific behavioural disturbances. In the absence of a trigger that causes positive symptoms to emerge, these non-specific disturbances might come to be viewed as symptoms of schizotypal, schizoid or avoidant personality disorders. In cases where positive symptoms are triggered, schizophrenia is fully expressed and the disturbances stemming directly from the underlying neuropathology manifest as negative symptoms. Thus, within this model, negative symptoms represent a direct manifestation of the biological vulnerability to schizophrenia. This biological vulnerability is proposed to be the primary cause of the social disability associated with psychosis.

Cornblatt et al.'s model is supported by evidence that negative symptoms often emerge before the onset of even attenuated positive symptoms (Manuel Cuesta, Peralta, Gil, & Artamendi, 2007; Häfner et al., 1999; Yung & McGorry, 1996), and that those diagnosed with schizophrenia often met criteria for schizotypal, schizoid and avoidant personality disorder before the onset of the disorder (Solano & De Chávez, 2000). Further, structural brain abnormalities are evident early in the course of psychosis (Steen, Mull, McClure, Hamer, & Lieberman, 2006) and have been found to predate the onset of positive psychotic symptoms in longitudinal studies of high-risk individuals (Pantelis et al., 2003).

Evidence of structural brain abnormalities at this early stage of disorder, before prolonged exposure to psychiatric medications, is clearly better evidence that these abnormalities may have a role in symptom expression than similar evidence obtained

in those with chronic psychosis. However, it remains unclear whether such brain abnormalities cause negative symptoms. Given that negative symptoms typically emerge before positive symptoms, it remains possible that these brain changes are a consequence of negative symptoms. A further possibility is that both negative symptoms and their associated brain abnormalities are epiphenomena of a currently unknown process.

The contention that it is an underlying vulnerability to psychosis that is the primary cause of the social disability associated with it is supported by evidence that negative symptoms predict poor longer-term functional outcomes in those at high risk of psychosis, whether or not they go on to develop positive symptoms (Lin et al., 2011). However, the claim that this vulnerability is neurobiological in nature is in need of verification. It is possible that the vulnerability to psychosis giving rise to negative symptoms and their associated adverse outcomes is conferred by psychosocial factors rather than neurobiology.

1.5.2. Neurocognitive Models of Negative Symptoms

Neurocognitive models suggest that negative symptoms are the result of cognitive impairments in specific domains. A number of theorists have suggested that impairments in the cognitive mechanisms that underpin goal-directed behaviour may be at the core of negative symptomatology. For instance, Frith (Frith, 1987; Frith & Done, 1988) proposed that individuals who present with negative symptoms retain the capacity for stimulus driven actions performed in response to changes in the environment but have reduced capacity for spontaneous, ‘willed’ actions intended to bring about particular goals. He hypothesised that while the *intention* to act is present in those with negative symptoms, the translation of this intention into action is disrupted due to faulty neural circuitry linking the prefrontal cortex and striatum.

Research investigating the neural substrates of negative symptoms lends some support to this theory; the frontotemporal and frontocorticostriatal circuits, the neural circuits most consistently linked to negative symptoms, are thought to play important

roles in the planning and organisation of goal-directed behaviours (Millan et al., 2014). Further, research carried out by Velligan et al. (2008, 2009) suggests that external cues can be successfully employed to prompt individuals with negative symptoms to initiate and complete behaviours that would not otherwise have been carried out. This supports the contention that spontaneous but not stimulus-driven actions are disrupted in those diagnosed with schizophrenia.

Barch & Dowd (2010) developed Firth's theory by suggesting that negative symptoms are the result of difficulties using internal representations of emotional experiences, anticipated rewards and future goals to guide behaviour. Their model draws on the affective neuroscience literature regarding the neural basis of the processes involved in converting internal representations to behaviour. These processes include 'liking' (hedonics), 'wanting' (reward prediction), cost-benefit analysis (the ability to represent the value of the outcome, compute the effort involved in achieving the outcome, and weigh the two against each other), and generating and executing a plan appropriate to achieve the intended outcome.

Barch & Dowd noted that those with negative symptoms do not seem to have any difficulty 'liking' since the hedonic responses of those with negative symptoms are comparable to those of controls when measured in laboratory conditions (Gard et al., 2007; Kring & Moran, 2008; Trémeau, Antonius, Nolan, Butler, & Javitt, 2014). However, there is evidence that individuals with prominent negative symptoms may have impaired reward anticipation, since they predict future life events will be less pleasurable in comparison to healthy controls despite finding them just as rewarding when they occur (Dowd & Barch, 2012; Gard et al., 2007). This has been conceptualised as anhedonia in schizophrenia comprising a deficit in *anticipatory* pleasure (pleasure related to the anticipation of future events) but not *consummatory* pleasure (pleasure when engaged in an enjoyable activity).

Impairment in reward anticipation may confer deficits in 'wanting', impacting the outcome of cost-benefit analyses. If an individual does not believe that performing an action will be rewarding then they are unlikely to deem even limited effort to be

worthwhile in achieving it. However, there is also emerging evidence that negative symptoms may be associated with abnormalities in the assessment of the cost of engaging in the actions necessary to obtain a rewarding outcome. Gold et al. (2013) found that whilst those with elevated negative symptoms were willing to make more effort for a higher value monetary reward, they were less likely than healthy controls to exert more effort when offered a 100% chance of reward than when offered a 50% chance of receiving the same reward. The authors hypothesise that this unexpected finding might be explained by a higher chance of reward increasing the salience of the effort required to achieve it in those with high levels of negative symptoms. As a result of this increased salience, the perceived effort required might neutralise the value attributed to an increased chance of reward.

Whilst Bard & Doward limit their model to the withdrawal subdomain of negative symptoms, Foussias & Remington (2010) suggest that impairment in the translation of internal representations into action may also be at the core of affective blunting and alogia. Foussias & Remington propose that all negative symptoms, including those within the diminished expression domain, are phenotypic manifestations of a pervasive reduction in appetitive drive. However, Hartmann et al. (2015) found that greater propensity to choose not to engage in rewarding but effortful behaviour was associated with the withdrawal subdomain of negative symptoms, but not with diminished expression. This suggests that the neurocognitive underpinnings of diminished expression may not be identical to those of withdrawal.

Indications of the possible neurocognitive underpinnings of diminished expression are provided by research demonstrating that individuals given a diagnosis of schizophrenia show deficits in the affective and cognitive capacities involved in empathy. Derntl et al. (2009) found that, relative to healthy controls, individuals meeting diagnostic criteria for schizophrenia show deficits in emotion recognition, emotional perspective taking and affective responsiveness. Contrary to the authors' expectations, those presenting with predominant negative symptoms were less impaired in these domains than those with predominant positive symptoms. This finding might prompt the hypothesis that negative symptoms function as a mechanism for coping with intense affective states in those experiencing

schizophrenia accompanied by intact affective responsiveness. However, the very small numbers in the subgroups compared ($n = 5$ for the subgroup with predominant negative symptoms) prevent firm conclusions from being drawn. In a subsequent study exploring the neural correlates of empathy deficits in schizophrenia (Derntl et al., 2012), decreased amygdala activation was found to correlate with negative symptom severity. Thus, it remains possible that deficits in emotion processing may be relevant to understanding affective blunting and/or alogia.

1.5.3. Cognitive Models of Negative Symptoms

Cognitive models of psychopathology posit that, whilst biological and social factors may create vulnerability to psychopathology, it is dysfunctional beliefs and appraisals that are its most proximal causes. Cognitive models of positive symptoms have received a good deal of research attention and are now supported by a substantial evidence-base (Garety & Freeman, 2013; Mawson, Cohen, & Berry, 2010). Cognitive models of negative symptoms on the other hand, have been developed only relatively recently and are thus supported by a less comprehensive (though growing) evidence-base.

Whilst formal cognitive models of negative symptoms are a relatively recent development, the idea that beliefs and appraisals may be relevant to understanding negative symptoms is not new. Bleuler (1950/1911) was the first to suggest that presentations that might today be described as negative symptoms may represent the individual's attempts to defend themselves against unbearable levels of stress (Kingdon & Turkington, 2005). This idea was developed by Strauss et al. (1989) who proposed that negative symptoms often reflect active coping in difficult psychological and social circumstances, the premise at the core of all subsequent cognitive models. Strauss et al. suggest that negative symptoms can helpfully be seen as understandable, and in some circumstances perhaps even adaptive, responses to the experience of psychosis (Table 1.2).

Table 1.2. Psychological factors proposed by Strauss et al. (1989) to contribute to negative symptoms.

Psychological Contributor	Description
Fear of relapse	An individual whose positive symptoms are exacerbated in stimulating environments may stop participating in valued activities to protect themselves from the pain of relapse.
Loss of hope and self esteem	A person who suffers from repeated psychotic episodes and experiences social and occupational decline may simply give up on life due to loss of hope and positive self-image.
Possibility of impulsive/bizarre behaviour	Apathy and withdrawal may serve to protect against public displays of bizarre or impulsive behaviour that might prove socially or personally destructive.
Problems finding a new identity	A person for whom being unwell has become central to their identity may withdraw due to difficulty establishing an identity distinct from their psychosis.
Guilt for past dysfunction	An individual who has experienced psychosis might feel guilt for their behaviour whilst unwell. This guilt may lead to withdrawal and demotivation.
Threat of complex/stressful social situations	Social and occupational situations are extremely stressful for some who have experienced psychosis. Negative symptoms might serve to reduce the threat of entering such stressful situations.
Helplessness due to overwhelming barriers to success	For some, barriers to improvement may seem insurmountable. Giving up in such circumstance might be adaptive in so far as it allows the individual to recruit help from others.

1.5.3.1. Kingdon & Turkington's Cognitive Model of Negative Symptoms (Kingdon & Turkington, 1994, 2005)

Drawing on the ideas of Strauss et al. (1989), Kingdon & Turkington developed an early cognitive model of negative symptoms. The model suggests that active attempts to cope with the stress imposed by altered perceptions, cognitive deficits, impaired identity and the expectations of others may be at the core of negative symptomatology. It is proposed that reductions in expressivity might reflect demoralisation and hopelessness, that avolition might reflect a reaction to overwhelming pressure and repeated failure, and that social withdrawal might be a mechanism for decreasing stress by reducing overstimulation. Kingdon & Turkington emphasise the protective nature of negative symptoms, stressing the importance of convalescence in the psychological healing process. They note that

healthy individuals often respond to unpleasant feelings, concentration difficulties, etc. by taking a break or switching to another activity. In contrast, those with schizophrenia are often encouraged to stubbornly persevere with tasks despite frustration and setbacks. They suggest that not allowing sufficient time for recuperation following a psychotic episode may prolong negative symptoms by increasing the perception of failure.

On the basis of this model, they encourage clinicians working with people with negative symptoms to sanction avoidance and set goals well below an individual's capability. While the model has not been the subject of direct empirical verification, trials of cognitive behavioural therapy based on treatment manuals incorporating Kingdon & Turkington's cognitive model of negative symptoms have been completed. These found significant effects on negative symptoms at both one year (Turkington et al., 2006; Turkington, Kingdon, & Turner, 2002) and five year follow-ups (Sensky et al., 2000; Turkington et al., 2008). However, since these trials were not accompanied by process evaluation, it is not possible to establish which components of these complex interventions led to the reductions in negative symptoms observed. As such, caution must be exercised in interpreting these results as providing support for Kingdon & Turkington's model of negative symptoms.

1.5.3.2. Beck et al.'s Cognitive Model of Negative Symptoms (Beck, Rector, Stolar, & Grant, 2008; Beck & Rector, 2005; Rector, Beck, & Stolar, 2005)

Beck et al.'s cognitive model takes its start from evidence of an association between negative symptoms and cognitive deficits. However, unlike neurocognitive models which propose that specific cognitive deficits account for negative symptoms directly, Beck et al.'s model asserts that neurocognitive impairments are indirectly associated with negative symptoms via their impact on an individual's beliefs and expectancies. According to the model, suffering neurocognitive impairments increases the likelihood of discouraging life experiences such as academic and social difficulties. These experiences of 'failure' result in a cognitive set characterised by dysfunctional beliefs and negative expectancies. These beliefs and expectancies lead

the person to disengage from other people and activities in an attempt to avoid further painful experiences. Thus, in common with other cognitive models of negative symptoms, Beck et al.'s model conceptualises negative symptoms as understandable but maladaptive attempts to cope with adverse circumstances. The model is depicted graphically in Figure 1.2.

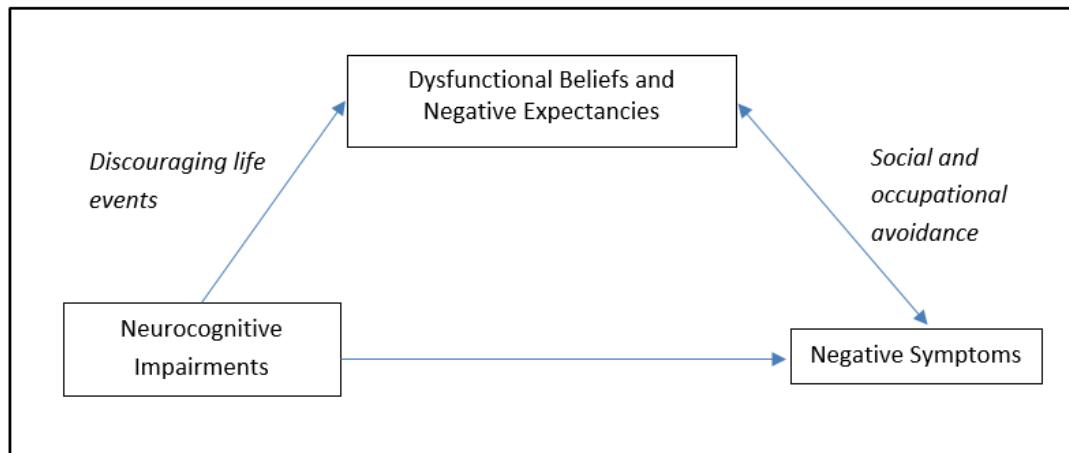


Figure 1.2. Diagrammatic representation of Beck et al.'s cognitive model of negative symptoms.

The dysfunctional beliefs and negative expectancies thought to be particularly relevant to the manifestation of negative symptoms include: defeatist performance beliefs (over-generalised negative conclusions about the significance of imperfect performance), social distancing beliefs (negative attitudes towards social affiliations), low expectancies for pleasure, acceptance and success, and perception of limited cognitive resources. The model suggests that the relationship between these beliefs and negative symptoms is bidirectional, with negative symptoms serving to reinforce the negative expectancies proposed to underlie them.

Empirical evidence for the relevance of dysfunctional cognitions to negative symptoms is beginning to accumulate, with defeatist performance beliefs having so far received most research attention. The relationship between defeatist performance beliefs and negative symptoms first received empirical support over a decade ago and was found to be independent of depression or positive symptoms (Rector, 2004).

At the time of writing, eleven further studies had been conducted investigating the association between defeatist performance beliefs and negative symptom severity. Ten of these were included in a recent meta-analysis (Campellone, Sanchez, & Kring, 2016) assessing the strength of the relationship between negative symptoms and defeatist performance beliefs; the meta-analysis revealed a small but significant effect. Further, Grant & Beck (2009) demonstrated that defeatist performance beliefs partially mediate the relationship between cognitive impairment and negative symptoms, as predicted by the model.

However, Campellone et al.'s meta-analysis found that only 5% of variance in negative symptoms could be explained by variance in defeatist performance beliefs. This would suggest that these beliefs play no more than a small role in the manifestation of negative symptoms. Since defeatist performance beliefs are only one type of dysfunctional cognition hypothesised to be relevant to negative symptoms, this finding does not present a major challenge to Beck et al.'s model. Nonetheless, it does caution against seeking to oversimplify the mechanisms underlying negative symptoms.

Social distancing beliefs are another dysfunctional cognition whose relevance to negative symptoms has received empirical support. Social distancing beliefs encompass negative attitudes towards social affiliations and a preference for solitary occupations. These beliefs have been found to be more common among those with schizophrenia than non-psychiatric controls (Blanchard, Mueser, & Bellack, 1998). Further, a longitudinal study by Grant & Beck (2010) demonstrated that baseline asocial beliefs, but not neurocognitive difficulties or poor emotion perception, predicted later social disengagement. The magnitude of this effect was greater than that of the prediction of future attitudes to social engagement from previous social functioning, suggesting that asocial beliefs might play a greater role in fostering asocial behaviour than vice versa.

Paralleling findings of decreased expectations of pleasure but intact hedonic capacity, an experience sampling study by Oorschot et al. (2013) found evidence for

greater asocial beliefs despite unaffected social experience in those with psychosis compared to healthy controls. Participants were asked to report their emotional experience and behaviour at unpredictable time points across six consecutive days. All participants displayed comparable emotional responses to the company of others, but those with psychosis (particularly those with higher levels of negative symptoms) were more likely to express that they would prefer to be alone when in company, and to choose to spend time alone. This finding would suggest that asociality in psychosis is not driven by reduced capacity for enjoying the company of others, but by asocial attitudes despite intact capacity for enjoyment.

Findings regarding hedonic capacity incorporated into neurocognitive models can also be interpreted as supporting Beck et al.'s model. Arguably, the deficit in anticipatory pleasure in schizophrenia discussed by neurocognitive researchers is better understood in terms of dysfunctional beliefs than reduced cognitive capacity. Strauss & Gold (2012) call attention to the fact that it is not just measures of anticipatory pleasure but all measures of non-current feeling, including retrospective, hypothetical, and trait measures, that suggest reduced pleasure in individuals given a diagnosis of schizophrenia. On the basis of these findings, they argue that apparent anhedonia in those with psychosis should be attributed to dysfunctional beliefs about the likelihood of obtaining pleasure and a consequent reduction in pleasure-seeking behaviour. Thus anhedonia in schizophrenia might be better understood as a consequence of low expectations for pleasure than a deficit in the capacity for pleasure, anticipatory or otherwise.

1.5.3.3. Staring et al.'s Cognitive Model of Negative Symptoms (Staring, ter Huurne, & van der Gaag, 2013)

Staring et al. developed an extension of the cognitive model proposed by Beck et al. within their cognitive behavioural therapy for negative symptoms treatment manual. The model as depicted in Staring et al. (2013) is reproduced in Figure 1.3.

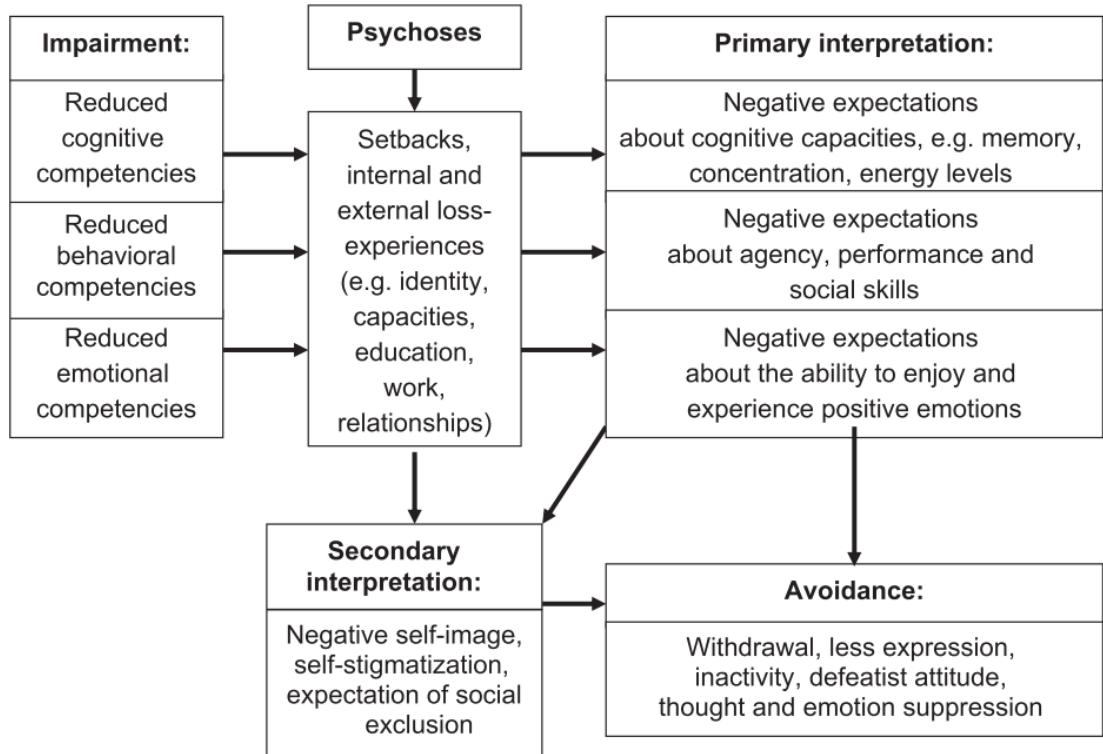


Figure 1.3. Staring et al.'s cognitive model of negative symptoms reproduced from Staring, ter Huurne, & van der Gaag (2013).

The model preserves a central role for negative expectations but also grants an important role for internalised stigma. Staring et al. suggest that individuals with experience of psychosis might be especially vulnerable to internalising stigmatising beliefs about mental ill-health as a result of the setbacks and losses that often accompany the disorder. They argue that this self-stigma might contribute to expectations of discrimination and social exclusion, leading to demoralisation and thus to the manifestation of negative symptoms. Evidence cited for the inclusion of stigma in the cognitive model of negative symptoms includes research demonstrating that high levels of self-stigmatising beliefs in conjunction with good insight predict demoralisation, hopelessness, low self-esteem and low quality of life (Cavelti, Kvrgic, Beck, Rüscher, & Vauth, 2012; Lysaker, Roe, & Yanos, 2007; Staring, Van der Gaag, Van den Berge, Duivenvoorden, & Mulder, 2009). Further support for the inclusion of self-stigma in the model is provided by a path analysis demonstrating that internalised stigma increases avoidant coping and active social avoidance via

decreased hope and self-esteem in those diagnosed with schizophrenia-spectrum disorders (Yanos, Roe, Markus, & Lysaker, 2008).

In addition, the range of discouraging experiences hypothesised to give rise to dysfunctional cognitions is extended within Staring et al.'s model. Whilst Beck et al. focus on the potential for social and occupational failures to negatively impact an individual's cognitive set, Staring et al. suggest that loss of identity and lessening of previous capabilities might also be relevant. Further, the factors proposed to contribute to discouraging experiences are expanded beyond neurocognitive impairments to include impairments in behavioural and emotional functioning. These extensions of Beck et al.'s model, whilst intuitively sound, remain in need of empirical verification.

1.6. TREATING NEGATIVE SYMPTOMS

1.6.1. Pharmacological Treatments

Antipsychotic medications remain the central pillar of the treatment of psychosis and schizophrenia (National Institute for Health and Care Excellence [NICE], 2014). However, whilst antipsychotic medications are effective in reducing positive symptoms, they have proved relatively ineffective in reducing negative symptoms (Tandon, Nasrallah, & Keshavan, 2010). The introduction of the second-generation antipsychotics was accompanied by much anticipation of a breakthrough in negative symptom treatment (Fleischhacker, 1995). However, whilst those marketing second-generation drugs often claim that they bring about "better negative symptom control than conventional antipsychotics" (Sernyak & Rosenheck, 2007), they have not been found to be consistently superior to first-generation antipsychotics in this regard (Leucht et al., 2009).

The modest improvements in negative symptoms sometimes observed in those treated with antipsychotics are likely conferred largely indirectly via their effect on positive symptoms. Improvements in negative symptoms during antipsychotic

treatment tend to coincide with improvements in positive symptoms (Tandon, Ribeiro, DeQuardo, & Goldman, 1993), and studies that have attempted to establish a direct effect of antipsychotics on primary negative symptoms have produced inclusive results (Murphy et al., 2006). Furthermore, extrapyramidal side-effects of antipsychotic medication are acknowledged to contribute to secondary negative symptoms (Carpenter et al., 1988). Thus, for an antipsychotic medication to have a net benefit on negative symptoms, decreases in negative symptoms must offset increases in negative symptoms due to extrapyramidal side-effects (Tandon et al., 2010).

The limited efficacy of antipsychotics in treating negative symptoms has led researchers to investigate a range of potential pharmacological adjuncts to antipsychotic medications. There is some evidence that adding antidepressants to antipsychotics may result in improvements in negative symptoms (Rummel-Kluge, Kissling, & Leucht, 2006). There is also preliminary evidence of a beneficial effect of a number of other agents, including dehydroepiandrosterone, deprenyl, galantamine, Ginkgo, methylene blue, naltrexone, selegiline, pergolide and essential fatty acids (Murphy et al., 2006). However, currently there is no conclusive evidence supporting the use of any adjunct agent in the treatment of negative symptoms. This is reflected in the absence of recommendations for the use of adjunct pharmacological agents for the treatment of negative symptoms from NICE guidelines (2014).

1.6.2. Non-Pharmacological treatments

The inadequacy of currently available pharmacological treatments for negative symptoms makes the development and implementation of effective psychosocial interventions all the more important. Non-pharmacological treatments whose effectiveness in reducing negative symptoms has been investigated include art therapies, social skills training, cognitive remediation therapy, cognitive behavioural therapy and exercise. The evidence in support of each of these intervention types will be reviewed in turn.

1.6.2.1. Art therapies

Art therapies involve working with a trained therapist to use artistic media, including visual arts, music, dance and drama, as a form of expression and communication to address emotional confusion or distress (Darton, 2013; The British Association of Art Therapists, n.d.). NICE first included a tentative recommendation to consider offering art therapies to individuals presenting with negative symptoms in the 2009 update of their guidelines for the treatment of psychosis and schizophrenia (NICE, 2014). This recommendation was based on the findings of six small-scale trials (Priebe et al., 2013) and was accompanied by a call for further research.

Since the 2009 NICE guidelines were published, two large trials of art therapies in schizophrenia have been completed. Crawford et al. (2012) randomised 417 outpatients to receive 12 months of either weekly group art therapy plus standard care, weekly group activity sessions plus standard care, or standard care alone. At follow-up, the three arms did not differ significantly on any of the primary outcomes, including negative symptom severity. Attendance at both the art therapy and activity groups were low. The study's authors concluded that, whilst art therapy may benefit 'a few highly motivated' people, offering art therapy to individuals diagnosed with schizophrenia in community settings does not lead to improved outcomes. Similarly, Priebe et al. (2016) randomised 275 participants to receive either Pilates (active control) or body psychotherapy, a form of art therapy facilitated by a qualified dance movement psychotherapist. The study found that body psychotherapy was no more beneficial for negative symptoms than was the control intervention. Despite these findings, the recommendation to consider offering art therapies to individuals presenting with negative symptoms was retained in the 2014 version of the NICE guidelines.

1.6.2.2. Social skills training

Social skills training consists of teaching designed to develop a range of skills important in interacting successfully with others (Kopelowicz, Liberman, & Zarate, 2006). These skills include assertiveness, conversation skills, medication control, job-hunting, recreational skills, family communication and conflict resolution (Morales Vigil, Orellana, García, & Correa, 2015). The techniques used to teach these skills include goal setting, modelling, behavioural rehearsal with corrective feedback, positive reinforcement, and homework to encourage generalisation of skills learnt (Kurtz & Mueser, 2008).

Although the primary goal of social skills training is improvement in psychosocial functioning, it has also been found to be effective in reducing negative symptoms. A meta-analysis of randomised controlled trials of social skills training for individuals diagnosed with schizophrenia-spectrum disorders carried out by Kurtz & Mueser (ibid.) found a medium average effect on negative symptoms. However, most of the evidence for the effectiveness of social skills training in alleviating negative symptoms is from non-UK trials (Elis, Caponigro, & Kring, 2013) and NICE currently recommend that social skills training should not be routinely offered to those experiencing psychosis (NICE, 2014). Given the relatively large evidence-base for social skills training as practiced in other countries, further UK-based research investigating the effectiveness of social skills training as a treatment for negative symptoms is warranted.

1.6.2.3. Cognitive Remediation Therapy

Cognitive remediation therapy (CRT) aims to enhance cognitive processes with the goal that improved cognition will lead to improvements in daily functioning (Wykes, Huddy, Cellard, McGurk, & Czobor, 2011). While the primary target of CRT is improved cognition, some studies have found evidence of an effect on negative symptoms (Bellucci, Glaberman, & Haslam, 2003; Gharaeipour & Scott, 2012). A meta-analysis of trials of CRT in schizophrenia suggested that the average effect on

negative symptoms is minimal (Wykes et al., 2011), however the results of a recent analysis suggest that this finding may be an artefact of inadequate measurement of negative symptoms (Cella, Reeder, & Wykes, 2014). Interestingly, it has been suggested that the effect of CRT on daily functioning may be mediated by reductions in negative symptoms, not by improvements in cognition (Farreny, Aguado, Ochoa, Haro, & Usall, 2013). This suggests that the mechanisms by which CRT leads to improvements in negative symptoms may be distinct from those that bring about improvements in cognitive functions.

1.6.2.4. Cognitive Behavioural Therapy

Cognitive behavioural therapy for psychosis (CBTp) developed from similar approaches used to treat common mental health problems such as depression. Like other forms of cognitive behavioural therapy, CBTp is built on the principle that it is not the events we experience that determine how we feel, but the way we interpret and respond to these events. According to cognitive models of positive symptoms, misattribution of unusual experiences triggered by stressful life events can account for psychotic symptoms themselves, and understandable but unhelpful reactions to these experiences for the distress and dysfunction associated with them (Freeman, Garety, Kuipers, Fowler, & Bebbington, 2002; Garety, Kuipers, Fowler, Freeman, & Bebbington, 2001; Morrison, 2001). Thus, intervening to change how an individual interprets and responds to unusual experiences might reduce symptoms, lessen distress and improve functioning.

The primary focus of CBTp is typically reducing distress associated with positive symptoms and most trials have investigated its impact on negative symptoms only as a secondary outcome (Wykes et al., 2008). Wykes et al.'s frequently cited meta-analysis (*ibid.*) investigated the impact of CBTp on a range of outcomes and found evidence of a moderate beneficial effect on negative symptoms when measured as a secondary outcome. However, a more recent meta-analysis looking specifically at the effect of CBTp on negative symptoms found the pooled effect of CBTp on

negative symptoms to be small (Velthorst et al., 2015). Larger effects were found to be associated with earlier year of publication and lower study quality.

Early trials of cognitive therapies specifically designed to target negative symptoms (CBTn) have shown promising results however. Grant, Huh, Perivoliotis, Stolar & Beck (2012) carried out a randomised controlled trial (RCT) of a cognitive therapy designed to target negative symptoms and poor psychosocial functioning in chronically low-functioning individuals given a diagnosis of schizophrenia. The therapy was based on Beck et al.'s cognitive model of negative symptoms and aimed to challenge dysfunctional beliefs about pleasure, cognitive abilities, performance and social functioning. Participants who received the trial intervention showed significantly greater reductions in avolition-apathy than the control group, as well as clinically significant improvements in functioning.

A non-controlled pilot trial of CBTn based on Staring et al.'s cognitive model of negative symptoms also produced encouraging results. Clinically important changes in negative symptoms were observed and there was a large within-group effect size on the PANSS negative subscale (Staring et al., 2013). Further, reductions in dysfunctional beliefs were found to partially mediate change in negative symptoms, lending support to the cognitive model underlying the intervention. However, a significant proportion of variation in negative symptom change was unexplained by the mediating variables considered, highlighting the gaps that remain in our understanding of the mechanisms underlying negative symptom change.

The MOVE programme (Velligan, Maples, Roberts, & Medellin, 2014) is a further promising intervention for negative symptoms. MOVE is a multicomponent psychological intervention for persistent negative symptoms based on a model that combines neurocognitive and cognitive explanations of negative symptoms. Key components of the intervention include antecedent control (using external cues to prompt specific behaviours), identifying and addressing deficits in anticipatory pleasure, enhancing emotional processing, skills building to address social and other skills deficits, and cognitive and behavioural techniques designed to target

dysfunctional beliefs. A recent pilot RCT of MOVE in individuals with persistent negative symptoms found a medium effect of the intervention immediately post treatment (Velligan et al., 2015). It remains to be seen whether these encouraging findings will be supported by larger trials, and whether any effects are maintained post-treatment.

1.6.2.4. Exercise

Exercise is defined within health research as physical activity that is planned, structured and repetitive, performed with the objective of improving physical fitness (Caspersen, Powell, & Christenson, 1985). Exercise has been observed to be an effective add-on treatment for individuals with psychosis, leading to improvements in a variety of domains including negative symptoms. Two independent meta-analyses of the effects of exercise interventions in non-affective psychosis have been recently published. Firth et al. (2015) examined the effects of exercise in individuals diagnosed with a non-affective psychotic disorder or experiencing a first episode of psychosis. They found a medium effect on negative symptoms of interventions incorporating exercise of moderate-to-vigorous intensity. Dauwan et al. (2016) examined studies of exercise interventions (including yoga) in individuals diagnosed with schizophrenia-spectrum disorders and also found a medium effect of exercise on negative symptoms. Yoga and aerobic exercise were found to be comparably effective in reducing negative symptoms.

These results suggest that exercise interventions are among the most effective currently available for negative symptoms. Moreover, qualitative evidence suggests that exercise interventions can be popular with young people experiencing a first-episode of psychosis provided they are tailored to the individual and incorporate adequate social support (Firth et al., 2016). However, the mechanisms through which exercise interventions influence negative symptoms remain unclear.

1.7. FIRST-EPIISODE PSYCHOSIS AND EARLY INTERVENTION

Psychosis usually emerges during adolescence or early adulthood with 80% of first psychotic episodes occurring before age 30 (Shiers & Lester, 2004; van Os & Kapur, 2009). However, for many years community services often neglected early psychosis, focusing instead on treatment-resistant psychosis and the rehabilitation of individuals who had developed severe and chronic disability (Birchwood, McGorry, & Jackson, 1997; Marshall & Rathbone, 2011). As such, chronic presentations tended to dominate the attention of both clinicians and researchers. Over the past two decades there has been a shift towards a greater proportion of therapeutic resources being allocated to individuals in the early phases of psychosis, in particular the first psychotic episode and its aftermath. This has been accompanied by a corresponding shift in research focus towards the identification, understanding and treatment of first-episode psychosis (FEP).

Increased interest in the early phase of psychosis was largely a response to research indicating that the first few years following psychosis onset may represent a ‘critical period’ during which ‘biological, psychological and psychosocial influences are developing and show maximum plasticity’ (Birchwood, Todd, & Jackson, 1998). Contemporary orthodoxy held that treatments for psychosis were merely palliative and could not influence the ‘natural history’ of the disorder (McGlashan & Johannessen, 1996). However, research demonstrated that much of the symptomatic and psychosocial deterioration that follows the onset of psychosis occurs relatively early on – within the first few years – and then plateaus (Birchwood et al., 1997, 1998). Further, it was observed that the early phase of psychotic disorders are highly responsive to treatment relative to more chronic presentations (Lieberman et al., 1993). Thus it was hoped that providing prompt treatment of the first episode might favourably influence the trajectory of the disorder by preventing or reducing early symptomatic and functional decline (Birchwood et al., 1997, 1998).

The critical period hypothesis inspired a sizeable body of research on the relationship between psychosis outcomes and duration of untreated psychosis (the time between

the first threshold psychotic symptom and commencement of appropriate treatment). Studies consistently found shorter duration of untreated psychosis to be associated with better outcomes, both symptomatic and functional (Marshall et al., 2005). This research provided the empirical justification for establishing specialist Early Intervention in Psychosis (EIP) services offering intensive, time-limited support to young people with FEP. Whilst there is a lack of consistent operationalised criteria to define the FEP population (Breitborde, Srihari, & Woods, 2009), in the context of EIP services (and the research reported in this thesis) it is used to refer to those presenting to mental health services with psychotic symptoms for the first time. Unlike the narrower concept of 'first-episode schizophrenia', an established diagnosis is not necessary to classify an individual as experiencing FEP, allowing for early diagnostic uncertainty (Department of Health, 2001).

In 2000, the UK government made the commitment that 'all young people who experience a first episode of psychosis, such as schizophrenia, will receive the early and intensive support they need' (Department of Health, 2000, p. 119). This commitment led to the implementation of the EIP service model throughout England in the ensuing years. EIP services are now widespread in Europe and Australia, and increasing in the United States (Birchwood et al., 2014). EIP services aim to provide age and phase appropriate care, incorporating pharmacological, psychological, social and occupational interventions (Department of Health, 2001; NICE, 2014). Treatment is provided in community settings or the service-user's own home, employing a modified version of the assertive outreach approach to maximise engagement (*ibid.*). EIP teams seek to normalise unusual experiences and offer hope for recovery, aiming to promote social recovery in addition to achieving symptom control (Birchwood et al., 2014). Services are founded on a core set of values including respect for the strengths of those experiencing psychosis, promotion of social inclusion, provision of responsive, person-centred care, and involvement of family and friends wherever possible (Bertolote & McGorry, 2005).

Whilst the theoretical rationale for early intervention is compelling, empirical support for EIP remains somewhat limited (Marshall & Rathbone, 2011). Qualitative research suggests that the service provided by EIP teams is valued by both service-

users and their families (Lavis et al., 2015; Lester et al., 2011). Further, a systematic review and meta-analysis of RCTs of EIP treatment indicated that EIP results in reduced hospital admissions, reduced symptom severity and improved relapse rates, as well as improving access to and engagement with services (Bird et al., 2010). The most recent Cochrane review of EIP services (Marshall & Rathbone, 2011) agreed that there is some evidence for the effectiveness of specialised EIP services. However, these reviews were limited by a paucity of available trials and by the methodological quality of the trials included; for instance the OPUS trial (Petersen et al., 2005), recognised by the Cochrane reviewers as the largest and highest quality trial of EIP, did not blind assessors to treatment allocation, introducing a substantial possibility of bias.

Improving functional outcomes following FEP is an important ambition of EIP services. Studies that have considered the impact of EIP on functional outcomes provide some support for a beneficial impact of EIP (Fowler et al., 2009a; Major et al., 2010; Singh et al., 2007). Nonetheless, rates of social recovery among those who receive treatment from EIP services remain stubbornly low (Hodgekins et al., 2015a; Morgan et al., 2014). Further, it is questionable whether any gains made whilst under the care of EIP services are sustained; follow-up studies suggest that positive effects observed immediately after EIP treatment are not maintained post discharge (Csillag et al., 2015; Marshall & Rathbone, 2011). For instance, in the OPUS trial the beneficial impact of EIP on both symptoms and global functioning observed at the end of 2 years of treatment (Petersen et al., 2005) was no longer evident 3 years later (Bertelsen et al., 2008). At 10 year follow-up, only 14% of the OPUS cohort met criteria for full recovery (both symptomatic and functional), and only 20% were engaged in either full- or part-time employment or education (Austin et al., 2013).

Thus whilst the EIP model offers benefits over conventional approaches to treating psychosis, scope for improving outcomes following FEP remains considerable. The factors that influence recovery from FEP are not fully understood but it has been suggested that negative symptoms may play a central role (*ibid.*). Elevated negative symptoms have been found to be a significant predictor of poor functional outcomes following FEP in both short and longer-term follow-up studies (Austin et al., 2013;

Hodgekins et al., 2015a; Milev, Ho, Arndt, & Andreasen, 2005). Conversely, low levels of negative symptoms early in the course of psychosis have been found to be a significant predictor of good symptomatic and functional recovery at five years (Albert et al., 2011). As such, targeting early negative symptoms as part of EIP treatment might be an important means of improving outcomes following FEP.

Unfortunately, negative symptoms in FEP remain under-researched and poorly understood, creating a significant barrier to the development of interventions to effectively target early negative symptoms. Most negative symptoms research carried out to date has focused on negative symptoms in individuals who have been unwell for many years and who meet diagnostic criteria for schizophrenia. It cannot be assumed that the findings of research conducted with participants with chronic schizophrenia can be applied to the population of EIP service-users. Current evidence suggests that negative symptoms are generally less persistent in FEP than in more chronic psychosis but, when they do show signs of persistence at this early stage, may be of particular prognostic significance (Galderisi et al., 2013; Malla & Payne, 2005). Further research is needed to build our understanding of negative symptoms as they occur in FEP in order to facilitate improved early intervention strategies.

1.8. SUMMARY AND RATIONALE FOR FURTHER RESEARCH

This chapter has introduced concepts that will be central to the thesis and sought to situate the research carried out within the wider clinical and academic context. Initially conceived as a core feature of schizophrenia, negative symptoms are now recognised to occur across diagnostic categories. The association between negative symptoms and poor outcomes following psychosis has prompted considerable growth in negative symptoms research since their 1980s ‘renaissance’. This growth has been accelerated by the development of a consensus regarding the parameters of the negative symptom construct and the creation of new tools for negative symptom measurement. A number of theoretical models of negative symptoms have been proposed, supported by a growing (but incomplete) evidence-base. The search for

effective treatment strategies is ongoing but there are a number of promising non-pharmacological approaches, including social skills training, cognitive therapy and exercise. The mechanisms through which such treatments might bring about improvements in negative symptoms are not fully understood.

The varying designs of the recently developed tools for negative symptom measurement reveal some remaining disagreement about the conceptualisation of negative symptoms. In particular, it is unclear whether experiential deficits should be viewed as essential to negative symptoms, or whether negative symptoms can be reduced to behavioural deficits and thus adequately measured via objective observations of behaviour. Evidence that individuals with psychosis have intact hedonic responses and social experience suggests that conceptualising negative symptoms as involving deficits in experiential capacity would be a mistake. This conclusion is supported by the limited correspondence between self-reported emotional range and observed negative symptom severity. Research investigating the experiential dimension of negative symptoms will be important in clarifying the phenomenology of negative symptoms, and thus how these symptoms are best conceptualised and measured.

It is becoming increasingly clear that dysfunctional attitudes and negative expectancies have a role in the manifestation of negative symptoms, and may account for the apparent experiential deficits observed in those with psychosis. The acceptance of a central role for dysfunctional cognitions in the manifestation of negative symptomatology entails that a cognitive model of negative symptoms be embraced. However, this is not to say that alternative models of negative symptoms should be dismissed. Human behaviour is complex and requires multiple levels of explanation. As in other domains of psychosis psychopathology, multi-modal intervention (incorporating both psychosocial and medical components) is likely to be necessary if negative symptoms are to be adequately treated. It is only by taking a biopsychosocial approach to understanding negative symptoms that such treatment strategies can be successfully developed.

Most of the currently available evidence regarding negative symptoms concerns individuals in the chronic phase of schizophrenia, with relatively little research effort having been directed towards understanding negative symptoms as they occur early in the course of psychosis. Given the association between elevated negative symptoms during FEP and poor functional outcomes, the incorporation of targeted interventions for those with elevated negative symptoms into the EIP treatment model has the potential to boost stubbornly low rates of social recovery. However, this will only be achieved if we more fully understand the early course of negative symptoms, the factors associated with early negative symptom persistence, and their relationship to poor social recovery during the early phases of treatment.

1.9. THESIS OVERVIEW

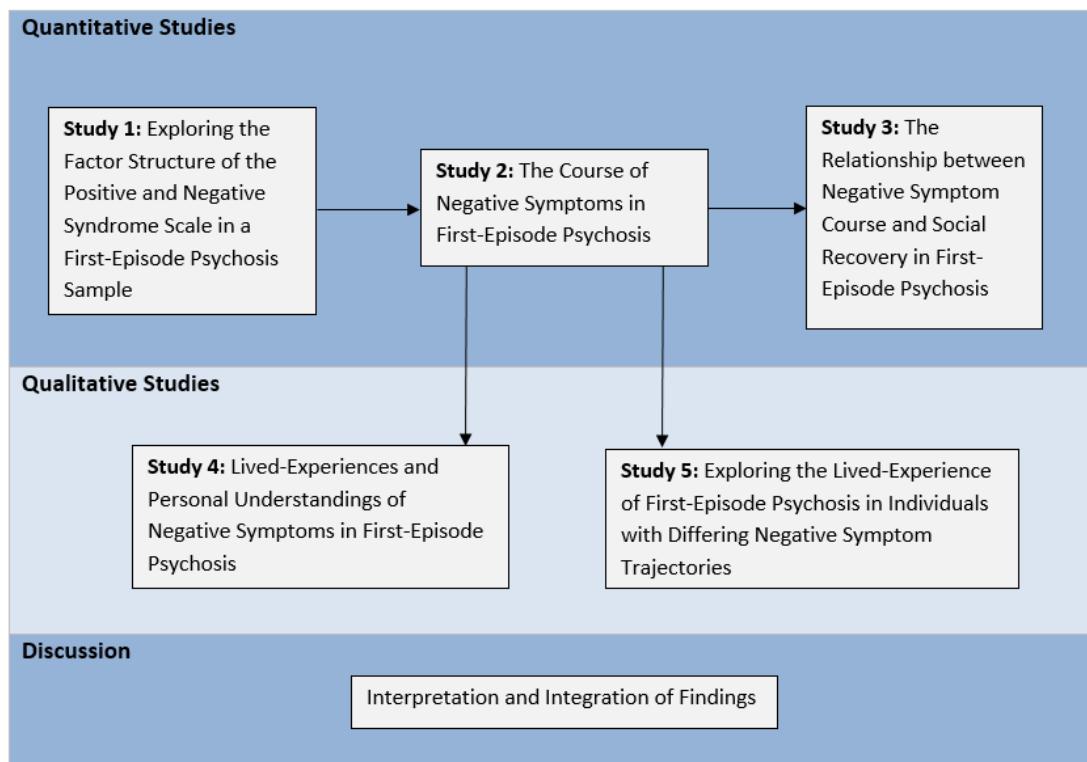
1.9.1. Research Design

This thesis aims to provide insights into the early course of negative symptoms in individuals under the care of EIP services. In order to facilitate a rich, multifaceted understanding of negative symptoms in FEP, and in line with the metatheoretical underpinnings of the research, the thesis takes a mixed methods approach.

Quantitative and qualitative methods are combined in a variation on a sequential explanatory design, in which quantitative and then qualitative data are analysed in separate but contingent phases (QUAN → QUAL; Cresswell, Plano-Clark, Gutmann, & Hanson, 2003).

In the first phase, quantitative data from a large FEP cohort ($n = 1006$) obtained using standardised assessment instruments are analysed statistically. In the second phase, qualitative data in the form of transcripts of in-depth interviews conducted with a subsample of members of the same cohort ($n = 24$) are analysed thematically. The results of the longitudinal modelling carried out during the first phase are important prerequisites of the second, informing the purposive sample of cohort members whose interview transcripts are analysed, and defining groups of participants with differing negative symptom trajectories whose experiences are

compared. The results of the quantitative and qualitative analyses are then integrated and interpreted in the light of existing research and theory. The overarching design of the research is depicted in Figure 1.4.



Note. An arrow between two studies denotes the study at the base of the arrow being a prerequisite of the study it points towards.

Figure 1.4. Diagrammatic representation of overall research design.

1.9.2. Structure of the Thesis

The thesis is divided into four parts. Part One comprises the current chapter and one further chapter addressing methodological issues. Part Two details the quantitative research conducted. The three studies reported in Part Two sought to facilitate the selection of PANSS items to measure the negative symptom construct (Chapter Three), identify distinct trajectories of early negative symptom progression and ascertain predictors of the trajectories identified (Chapter Four), and examine the relationship between these early negative symptom trajectories and early social recovery (Chapter Five). Part Three of the thesis reports the qualitative research

conducted. The two studies described in Part Three explore the lived-experience of those whose negative symptoms followed the distinct courses identified in Part Two. The studies address experiences and understandings of negative symptoms themselves (Chapter Six), and the way in which individuals with differing early negative symptoms trajectories make sense of their psychosis, describe the treatment they received and the process of recovery (Chapter Seven). Parts Two and Three are intersected by a short bridging section (Interlude) which presents the rationale for the use of qualitative methods to complement the quantitative work conducted. Part Four comprises a single closing chapter (Chapter Eight) which focuses on integrating the quantitative and qualitative findings, relating them to the wider literature, evaluating their significance and discussing their potential theoretical and clinical implications.

Chapter Two – Methodological Considerations

2.1. OVERVIEW

This chapter addresses a number of important issues pertaining to the methodology of the research described in the ensuing five chapters. After first outlining the ontological and epistemological stance underpinning the research, the context in which the data were collected is described and ethical issues concerning secondary data analysis discussed. Finally, reflexivity is addressed through reflection on the impact of my own personal background and beliefs, and those of others, on the research process and findings.

2.2. METATHEORETICAL FOUNDATIONS

All scientific research is underpinned by ontological and epistemological assumptions: assumptions about the nature of the reality being investigated and the means of acquiring knowledge of this reality. Mixed methods research combines research paradigms whose proponents traditionally take contrasting ontological and epistemological positions. As such, whereas the metatheoretical position of the researcher is often taken for granted in quantitative investigations, the adoption of a mixed methods approach requires that the researcher's ontological and epistemological positions are explicitly acknowledged.

The ontological and epistemological foundations of the research described in this thesis are provided by critical realism. Proponents of critical realism acknowledge the existence of an objective reality but assert that our knowledge of this reality is conceptually mediated, that is, our understanding of the world is always filtered through language and concepts that are relative and changeable across time, cultures and individuals (Danermark, Ekström, Jakobsen, & Karlsson, 2002). The critical realist approach is motivated by a desire to acknowledge the untenability of the naïve realist's acceptance of the existence of neutral empirical 'facts', whilst preserving the possibility of scientific explanation of human phenomena (*ibid*).

The critical realist is an ontological realist, that is he or she accepts the existence of a reality independent of the observer, but rejects the empiricist's reduction of reality to the observable (Collier, 1989). Critical realism emerged from the philosophy of science of Bhaskar (1975, 1979) who asserted that it is possible to distinguish three ontological domains: the empirical (what we experience), the actual (events that happen whether we experience them or not), and the real (generative mechanisms with the potential to bring about events in the world). Bhaskar emphasised the importance of this third ontological domain to scientific endeavour; he argued that only by acknowledging the reality of unobservable generative mechanisms is causal explanation of observed phenomena made possible (Danermark et al., 2002). For the critical realists, to have knowledge entails understanding the unobservable mechanisms that produce empirical events, not just the events themselves.

Since generative mechanisms – the central object of scientific inquiry according to the critical realist – are not directly observable, we can only understand them through proposing theoretical models. However, this does not preclude the possibility of acquiring scientific knowledge through observation; empirical testing plays a central role in the epistemology of critical realism. Whilst the critical realist accepts that all such theories are fallible and subject to revision, they assert that theories should be evaluated according to their ability to explain observed regularities. Thus knowledge can be acquired through the process of proposing theoretical explanations and rejecting those that do not adequately account for one's observations in favour of theories that prove less fallible.

The choice of critical realism as the metatheoretical grounding of this thesis is partly informed by its subject matter. Psychotic phenomena offer a rare insight into the gap between subjective experience and external reality; that it is possible to have hallucinatory experiences demonstrates that our perceptions of the world are not direct representations of it, making a position of naïve realism impossible to maintain. However, the possibility of distinguishing delusional from veridical understandings of the world demonstrates our collective capacity to use empirical evidence to reveal the fallibility of particular ways of understanding the world

around us. Furthermore, the nature of psychiatric concepts provides strong support for the metatheoretical claims of critical realism. Psychiatric concepts (symptoms, diagnoses, treatment models, etc.) are not empirical facts, but nor are they abstract theories with no grounding in reality. Instead they provide a conceptual scaffolding intended to help users make sense of biological, psychological and social phenomena observed in connection to mental distress and dysfunction.

It would be inappropriate to approach research concerning such phenomena from a perspective which assumes direct, unmediated access to the object of study. Equally, for research to remain a worthwhile endeavour it is important not to preclude the possibility of judging any theory to be more or less true than another. Critical realism allows that we can judge the merits of a psychiatric conceptualisation or theory according to how far it concurs with our observations of reality, without considering the knowledge so acquired indubitable.

The adoption of a critical realist stance was also motivated by the need to provide firm philosophical groundings for a mixed methods approach. Much early unease about mixed methods research concerned the differing philosophical foundations of quantitative and qualitative approaches. It was argued that since quantitative and qualitative methods emerged from paradigms with incompatible ontological and epistemological assumptions, mixing these methods is neither sensible nor possible (Greene, Caracelli, & Graham, 1989). Mixed methods research has often been based on a pragmatic approach in which practicality and usefulness take precedence over ontological and epistemological considerations (Tashakkori & Teddlie, 1998). However, critics of this approach warn that attempting to divorce method from metatheory is futile: all research makes assumptions about the nature of the object of study and the means by which knowledge of it can be obtained, whether they are explicitly acknowledged or not (Danermark et al., 2002).

Critical realism provides solid metatheoretical foundations for mixed methods research since it holds that generative mechanisms are not just constant conjunctions of observed events but a domain of reality. As such, understanding the world as it is

requires not just ‘extensive’ inquiry, aimed at describing empirical regularities, but also ‘intensive’ inquiry, aimed at generating theories regarding the processes underlying the regularities observed (*ibid.*). As such, a critical realist perspective suggests the tandem utilisation of qualitative and quantitative methods as the approach most likely to facilitate deep understanding of reality.

2.3. DATA COLLECTION: THE EDEN RESEARCH PROGRAMME

This thesis makes use of data collected as part of the EDEN research programme (Birchwood et al., 2014). EDEN was a multisite, multi-phase, mixed-methods research programme funded by the Department of Health (2005-2010 and extended 2011-2016). The programme was designed to evaluate the implementation, impact and cost-effectiveness of EIP services in the UK, and to develop an explanatory model of variance in patient outcomes (*ibid.*). Participants were recruited from EIP services in five purposively selected sites: Birmingham, Cambridgeshire, Cornwall, Lancashire and Norfolk. Sites were selected to reflect national diversity in urbanicity and service configuration. All individuals recruited into participating EIP services between August 2005 and April 2009 were invited to take part. Since the programme was designed to assess outcomes of EIP services, no special inclusion criteria were set beyond the individual having been accepted by one of the participating services (although those who had not experienced an episode of psychosis and had been accepted into services on account of being at high-risk of psychosis were excluded). Of those service-users eligible for participation, 49% (1027 individuals) consented to take part. Participants did not differ significantly from non-participants in terms of age, gender, ethnicity or marital status (*ibid.*).

In the first phase of the programme – National EDEN – participants were assessed using a battery of quantitative assessment measurements within 3 months of entry into EIP services (baseline), and again six and twelve months later. National EDEN also included a qualitative component designed to assess the acceptability of services. A purposive sample of service-users and family carers were interviewed within six months of entry to EIS and twelve months later. Further, annual focus

groups with EIP staff were conducted, concentrating on their views on barriers and facilitators to service implementation.

The second phase of the research programme – Super EDEN – began in 2011. During this phase, the cohort were followed-up annually for a further two year period in order to assess outcomes at the end of, and post discharge from, EIP. In addition to re-administering the quantitative assessment battery used during National EDEN at a further three to four time points, Super EDEN involved a substantial qualitative component involving a series of in-depth interviews with both participants and family carers. A total of 518 service-users consented to participate in Super EDEN, with 207 of them choosing to take part in its qualitative component, along with 98 of their family carers. The quantitative studies in this thesis use data from the first phase of the programme (National EDEN), and the qualitative studies data from the second phase (Super EDEN).

2.4. ETHICAL CONSIDERATIONS

Ethical approval for the EDEN programme was granted by Suffolk Research Ethics Committee (reference number: 05/Q0102/44) and by the local research governance department at each of the participating research sites. Individuals invited to participate were provided with a written information sheet (Appendix B) detailing the purpose of the research programme, what participation would involve, the possible risks and benefits of taking part, and information about how confidentiality would be safeguarded. The information sheet also emphasised the right to decline participation or withdraw from the study at any time, and explained that a decision not to take part or to withdraw would not adversely affect the clinical care received. Potential participants were also provided with a verbal explanation of the research and had the opportunity to have their questions answered.

Individuals who wished to participate were asked to complete a consent form to provide a written record of their informed consent. In the case of participants under the age of 16, the informed consent of the young person was supplemented by the

informed assent of a parent or legal guardian. Renewed informed consent was sought and recorded prior to the second phase of the programme. Participants received £20 per quantitative assessment and £10 per in-depth interview to compensate them for their time and were reimbursed for any travel expenses.

To protect participants' confidentiality, each individual was allocated an identifier code. Identifiable participant information was removed from study data and replaced with the identifier code such that data from a single participant could be matched without the participant's identity being revealed. Raw data is stored in locked filing cabinets in secure locations at participating sites. Consent and assent forms and all other documents containing participant identifiable information are stored separately from anonymised data. All electronic data is stored in password protected locations to prevent unauthorised access and data transferred between sites using a secure file transfer system.

Since participants were not required to undertake any additional procedures for the purposes of the current research, there was minimal additional risk to, and no additional burden on, participants. Nonetheless, the secondary analysis of existing data is not ethically unproblematic and should not be undertaken without careful consideration of the relevant ethical issues.

Secondary analysis can be defined as 'the utilisation of existing data, collected for the purposes of a prior study, in order to pursue a research interest which is distinct from that of the original work' (Heaton, 1998). Codes of ethical research practice suggest that consent should not be considered a 'once-and-for-all' event prior to data collection, but an ongoing process (Grinyer, 2009). The British Psychological Society's guidelines on informed consent (The British Psychological Society, 2009) recommend that psychologists should, after obtaining initial informed consent to the full extent allowed by the capacity of the individual concerned, 'obtain supplemental informed consent as circumstances indicate, when professional services or research occur over an extended period of time, or when there is significant change in the nature or focus of such activities' (p. 13). Such guidelines suggest that it may be

necessary to obtain supplementary informed consent prior to secondary analysis of a participant's data. As such, the decision not to seek additional consent prior to carrying out the research described in this thesis is in need of justification.

Decisions about whether secondary analyses of data require additional consent largely hinge on whether the intended use of the data is sufficiently distinct from that initially intended to invalidate the original contract between participant and study team. The British Psychological Society guidelines suggest that supplementary consent should be sought when 'there is significant change in the nature or focus of' the research, however the definition of 'significant change' in this context is unclear. Determining whether a change in focus is significant is particularly difficult when, as in the EDEN research programme, the initial aims of a project were broad. Whilst the primary remit of the EDEN programme was the evaluation of EIP services, the development of an explanatory model of variance in patient outcomes was also a stated aim of the programme. Given the close relationship between negative symptoms and outcomes, investigating negative symptoms is of clear relevance to this aim. As such, an argument can be made that the studies described in this thesis fall within the scope of the original aims of the programme and so do not represent a significant change in the focus of the research.

Whilst it is clearly ethically important that participants are adequately informed about the use that will be made of their data, this must be balanced against the demands made of them. Participants are not usually required to have a detailed understanding of the analysis plan of a study before agreeing to participate since this requirement would impose undue burden. As such, requesting supplementary consent to conduct additional analyses in line with the initial aims of the project would be rather odd given that few participants would have been aware of the original analysis plan. Further, repeated requests for additional consent would place increased demands on participants' time and might be perceived as a nuisance by some. Arguably, researchers have a duty to respect the time and efforts of their participants by using their data to the full. For some participants, greater volume of research outputs might make their participation more worthwhile (Grinyer, 2009).

Additionally, since much research (the EDEN programme included) is funded by public money, researchers have a responsibility to the wider public to ensure that the data they generate is fully utilised. Using public money to carry out a primary study with research questions that could be adequately addressed through analysis of pre-existing data would not be easy to justify (Research Councils UK, 2015). Requiring additional consent to be provided for all secondary analyses would be a significant barrier to the efficient use of public resources.

2.5. REFLEXIVITY: THE ROLE OF THE RESEARCHER IN THE RESEARCH

Reflexivity is the process of engaging in explicit, self-aware reflection on one's personal impact on the process and outcomes of research (Finlay, 2002). Critical realism entails an epistemological relativism in which the possibility of attaining objective knowledge is rejected. Thus the products of research are acknowledged to be subjective interpretations of reality, not objective representations (Wikgren, 2005). Whilst there might be empirical grounds for judging some interpretations superior to others, researchers taking a critical realist perspective must avoid falling into the trap of believing that the products of their research are neutral facts. We each occupy a unique vantage point, influenced by our past experiences and social, cultural and historical context, and it is only from this vantage point that we can experience and interpret the world. Through acknowledging the role of the researcher in the research process and the subjectivity of its outputs, the transparency of the research process and the integrity of its findings can be maximised. Further, by making one's 'conceptual baggage' explicit, another dimension of the research is revealed, one that is always present but often unacknowledged (Kirby & McKenna, 1989).

My interest in early psychosis began when, as a recent graduate, I was lucky to secure a position as an Assistant Psychologist within Central Norfolk Early Intervention Team (CNEIT). During my time with CNEIT, I had the privilege of meeting many young people experiencing FEP. I was moved by their courage and

resilience, and fascinated by the ways they sought to come to terms with, and make sense of, their experiences. Many of CNEIT's clients were a similar age to me but were faced with circumstances that, not having experienced psychosis personally, I could scarcely imagine. I was also inspired by the dedication, compassion and insight of my CNEIT colleagues, many of whom had been integral in establishing the service. In common with other EIP services, CNEIT adopts a normalising, non-pathologising approach to psychosis. The service the team provides is holistic, encompassing physical and social as well as psychological needs, and is tailored to the priorities of the client (Social Care Institute for Excellence, 2011).

The non-pathologising, person-centred ethos of the team shaped my understanding of psychosis and its treatment. I came to believe that psychotic symptoms are often understandable reactions to extreme circumstances, can be understood in terms of ordinary psychological processes, and are usually meaningful to those experiencing them. I learnt that whilst reducing or eliminating psychotic symptoms is often important to young people and their families, other aspects of life, including work, education, housing, family and peer relationships are frequently just as, if not more, important.

My motivation to study negative symptoms was founded on the realisation that it is often negative and not positive symptoms that prove most enduringly disruptive to the lives of individuals who experience psychosis. I found it surprising that, whilst positive symptoms are now widely understood to lie on a continuum with experiences that are common across the population, the same is not true of negative symptoms. Nearly everyone, whether they have experienced mental health problems or not, will encounter periods during which they don't feel much like talking, lack motivation or prefer not to be around others. As such, it struck me as odd that when individuals with psychosis present with similar phenomena, these are taken to be fundamentally different from these 'ordinary' negative symptom-like experiences.

At the time I joined CNEIT, the second phase of the EDEN programme was just getting underway. I was tasked with re-contacting members of the cohort from the

Norfolk site and inviting them to participate in the next phase of the study. Over the next 18 months I conducted both quantitative assessments and qualitative interviews with EDEN participants alongside my role within the clinical team. As such, I did not approach the EDEN data as an impartial outsider; I had formed impressions of the participants I met during data collection and had already begun to develop ideas about the nature of negative symptoms in this cohort. My experiences working with young people with non-psychotic mental health problems after leaving CNEIT also served to reinforce my impression that negative symptoms in those with psychosis may not be fundamentally different from similar phenomena in those without experience of psychosis.

The impact of my own personal experiences and beliefs on the research is most apparent when considering the studies employing qualitative methods. My choice of research questions was certainly influenced by the interests I developed and the questions that arose during my time with CNEIT. Furthermore, although I made efforts to ensure that my analysis was firmly grounded in the data throughout, my approach to analysis, interpretation of the data and selection of themes will have been influenced by my ‘conceptual baggage’.

The role of the researcher in shaping quantitative research is less often acknowledged but no less pertinent (Ryan & Golden, 2006). In the case of the quantitative research described in this thesis, there was perhaps more room for my own personal background and beliefs to influence the conclusions reached than in most quantitative studies due to the statistical methods employed. Since selection of the optimal model of negative symptom trajectory classes involved weighing statistical considerations against subjective judgements of parsimony and interpretability, it is possible that a different researcher would have selected an alternative model as optimal and thus reached different conclusions.

Given that the research described in this thesis involved analysis of data collected, in the most part, by others, a complete consideration of reflexivity in this case requires reflection on the role in shaping the research of all those involved in data collection

in addition to myself. Collecting data on the lives of individual people, whether quantitative or qualitative in nature, is a complex, dynamic process influenced by multi-layered power dynamics (*ibid.*). The Research Assistants working on the EDEN programme were from diverse backgrounds, both professionally and personally, each bringing with them a unique set of experiences, values and beliefs. Given the complexity of the social interactions involved in producing the data, it is impossible to establish the impact of the individual attributes of the many researchers involved on the conclusions reached. This impossibility supports the critical realist insistence on avoiding regarding the products of research as objective representations of reality.

2.6. SUMMARY

This chapter has described the critical realist underpinnings of the research, described the EDEN research programme through which the data were collected, and argued for the ethical justification of secondary analysis of this data in the absence of additional informed consent. The final section of the chapter aimed to address the reflexivity inherent in psychological research through explicitly addressing my own and other researchers' impact on the process and products of the research. The five chapters that follow report the empirical research conducted.

PART TWO

A Quantitative Investigation of Negative Symptoms in First-Episode Psychosis

Chapter Three – Exploring the Factor Structure of the Positive and Negative Syndrome Scale in a First-Episode Psychosis Sample

3.1. BACKGROUND AND RATIONALE

The PANSS (Kay, Fiszbein, & Opler, 1987) is one of the most widely used measures of psychopathology in psychosis research, and was the only measure of negative symptom severity included in the EDEN battery. The PANSS is a 30-item instrument designed to measure a wide range of symptoms associated with schizophrenia. Symptom severity over the previous seven days is assessed by a trained rater on the basis of a semi-structured interview with the participant and the reports of professional carers or family members. Each symptom is rated on a 7-point scale from 1 (absent) to 7 (extreme) according to a set of symptom-specific anchoring criteria.

The PANSS items were originally grouped into three subscales: positive symptoms, negative symptoms and general psychopathology. However, it is now accepted that these a priori subscales are not an accurate reflection of the scales underlying factor structure (Kay, Opler, & Fiszbein, 2000). Numerous principle component analyses of the PANSS have been conducted, typically yielding four to seven factors, of which one corresponds to the negative symptoms construct (Fitzgerald et al., 2003). The negative symptoms factors identified by these analyses vary (Emsley, Rabinowitz, & Torreman, 2003; Wallwork, Fortgang, Hashimoto, Weinberger, & Dickinson, 2012), but none align with the original negative subscale. Indeed, it is now widely accepted that the PANSS negative subscale contains several items measuring symptoms that do not fall within the domain of negative symptoms (Kirkpatrick et al., 2006). As such, the negative subscale of the PANSS is an unsatisfactory tool for the assessment of negative symptom severity.

Due to the limitations of the original PANSS subscales, it is becoming increasingly common for studies using the PANSS to utilise a bespoke subscale structure based on a published factor model (Nicotra, Casu, Piras, & Marchese, 2015). However,

there remains much controversy surrounding the factor structure of the PANSS (Malaspina et al., 2014), making the choice of factor model to employ in using this strategy less than straightforward. Studies investigating the factor structure of the PANSS in schizophrenia have most commonly identified models with five factors, and the five-factor ‘pentagonal model’ (White, Harvey, Opler, & Lindenmayer, 1997) developed by the PANSS study group was included in the most recent PANSS manual (Kay et al., 2000). However, a subsequent independent study found that this model was an inadequate fit for data from a sample of 347 individuals diagnosed with schizophrenia (Fitzgerald et al., 2003). A recent attempt has been made to construct a ‘consensus’ five-factor model through identifying the most common item-factor assignments among 29 independent five-factor models (Wallwork et al., 2012). The resulting factor structure was found to be a good fit to data obtained from two independent samples from differing cultural backgrounds.

Such a consensus factor structure might be considered a suitable basis for the formation of a negative symptoms subscale for use in this thesis. However, Wallwork et al.’s samples included only individuals with an established diagnosis of either schizophrenia or schizoaffective disorder and who were, on average, more than a decade older than the EDEN cohort. It cannot be assumed that a factor model confirmed in an older, diagnostically homogeneous sample can necessarily be successfully applied to an FEP cohort. Substantiating this assertion, Langeveld et al. (2013) examined the fit of five widely used PANSS factor models (including Wallwork et al.’s consensus model) in a large FEP sample ($n = 588$) and found that none of the models tested met criteria for satisfactory model fit.

Use of PANSS symptom subscales based on an inadequate factor model may result in suboptimal sensitivity to change. As such, it is important to determine the best-fitting factor model for the population of interest when determining symptom subscales. Given a lack of a consensus regarding the optimum factor model of the PANSS in an FEP sample, the decision was taken to carry out a study to determine the factor structure of the PANSS in the EDEN cohort itself rather than choosing a published factor model. The factor model identified could then be used to determine the most suitable PANSS items to measure negative symptom severity for the

purposes of this thesis. This approach has been recognised as a valid means of ascertaining an appropriate subscale structure for the PANSS for the particular sample under investigation (Nicotra et al., 2015).

It should be noted that while none of the PANSS factor structures developed in schizophrenia samples were an adequate fit for Langeveld et al.'s FEP data, neither was the one factor structure developed in a sample with recent-onset psychosis. Thus their failure to confirm the published factor structures considered may represent a wider problem of lack of stability of PANSS factor structures across samples. A study that examined the goodness-of-fit of all previously published five-factor models of the PANSS in a sample of 5769 individuals diagnosed with schizophrenia failed to confirm the appropriateness of any of the models considered (van der Gaag et al., 2006a).

An important limitation of much work exploring the factor structure of the PANSS to date is the use of restrictive models that do not allow for the free estimation of cross-loadings, thereby restricting each item to load on only one factor. Some authors suggest that allowing free estimation of cross-loadings is necessary to adequately reflect clinical reality and thus obtain satisfactory model fit (van der Gaag et al., 2006b; van den Oord et al., 2006). Following their failure to confirm any of the published five-factor models identified in the literature, van der Gaag et al. (2006b) used ten-fold cross-validation to develop a revised five-factor model. Ten-fold cross-validation involves randomly assigning participants to one of ten equally sized subsamples. Nine of these subsamples serve as training sets and the remaining subsample is used to test the validity of the resulting model. This process is then repeated with each of the subsamples in turn serving as the validation set.

Using this method, van der Gaag et al. demonstrated that a five-factor model can achieve good fit when items are permitted to load on more than one factor. Perhaps more importantly, they demonstrated the stability and clinical face-validity of such cross-loadings, indicating that they may be necessary due to some symptoms having multiple causes rather than certain PANSS items simply being ill-defined. The

negative symptom factor they identified was particularly stable; eight PANSS items – ‘blunted affect’ (N1)¹, ‘emotional withdrawal’ (N2), ‘poor rapport’ (N3), ‘apathetic social withdrawal’ (N4), ‘lack of spontaneity and flow of conversation’ (N6), ‘motor retardation’ (G7), ‘uncooperativeness’ (G8) and ‘active social avoidance’ (G16) – loaded on the negative factor in all 10 cross-validations.

Van den Oord et al. (2006) also recognised the disadvantages of modelling the structure of the PANSS using restrictive models and thus used a combination of exploratory and confirmatory factor analysis to develop and assess the fit of a model that allowed items to load on multiple factors. The ‘Negative’ factor in the six-factor model they obtained was indicated by the items ‘blunted affect’ (N1), ‘poor rapport’ (N3), ‘motor retardation’ (G7) and ‘disturbance of volition’ (G13). However, the factor labelled ‘Withdrawn’ by the authors, indicated by ‘active social avoidance’ (G16), ‘emotional withdrawal’ (N2) and ‘apathetic social withdrawal’ (N4), could also be argued to reflect the negative symptoms construct.

For ease of comparison, the negative symptoms factors in van der Gaag et al. and van den Oord et al.’s models are presented alongside the negative factors from White et al.’s pentagonal model and Wallwork et al.’s consensus model in Table 3.1.

¹Each PANSS items was labelled by the scale’s authors with a combination of a letter and a number. The letter denotes which of the original subscales it formed part of (‘P’ for the positive subscale, ‘N’ for the negative subscale, and ‘G’ for the general psychopathology subscale).

Table 3.1. Summary of PANSS items assigned to the factor corresponding to the negative symptoms construct in four competing factor models.

PANSS Item	White	Wallwork	Van der Gaag	Van den Oord
N1 Blunted affect	✓	✓	✓	N
N2 Emotional withdrawal	✓	✓	✓	W
N3 Poor rapport	✓	✓	✓	N
N4 Passive withdrawal	✓	✓	✓	W
N6 Lack of spontaneity	✓	✓	✓	
G5 Mannerisms and posturing	✓			
G7 Motor retardation	✓	✓	✓	N
G8 Uncooperativeness	✓		✓	
G13 Disturbance of volition	✓			N
G14 Poor impulse control	✓			
G16 Active social avoidance			✓	W
<p>‘✓’ = included in a single negative symptoms factor ‘N’ = included in van den Oord et al.’s ‘Negative’ factor ‘W’ = included in van den Oord et al.’s ‘Withdrawal’ factor</p>				

Note. Complete citations for the factor models compared are White et al. (1997), Wallwork et al. (2012), van der Gaag et al. (2006b) and van den Oord et al. (2006).

Several factor models were fitted to the data in the current study. Initially, exploratory factor analysis (EFA) was used to generate a factor model and confirmatory factor analysis (CFA) used to test how well this model fitted the data. The advantage of this approach is that if it were possible to identify a factor model with adequate fit to the data using CFA then a single structural equation model incorporating both the measurement model for negative symptoms and longitudinal growth analyses would be able to be specified in the subsequent study. However, if (as was anticipated on the basis of the work by van der Gaag et al. and van den Oord et al. discussed above) it proved impossible to confirm the fit of the model suggested

by EFA using CFA, it was planned that exploratory structural equation modelling would be employed to determine the factor structure instead.

Exploratory structural equation modelling (ESEM) is a relatively new modelling technique (Asparouhov & Muthén, 2009) which combines advantages of both confirmatory and exploratory factor analysis (Marsh, Morin, Parker, & Kaur, 2014). Like EFA, ESEM does not require cross-loadings to be fixed at zero, allowing for the sort of complex factor models that van der Gaag et al. and van den Oord et al. argue are necessary to adequately reflect clinical reality and thus obtain satisfactory model fit. However, unlike EFA and in common with CFA, model fit indices can be obtained using ESEM, enabling the adequacy of the fit of the model to the data to be verified.

3.2. RESEARCH QUESTION

What is the optimum factor model of the PANSS in a sample of EIP service-users and which items indicate the factor (or factors) in this model corresponding to the negative symptoms construct?

3.3. METHODS

3.3.1. Design

PANSS data from a large sample of individuals with FEP were explored using factor analytic techniques. Participants were assessed using the PANSS within 3 months of entry into participating EIP services. This study employed a cross-sectional design: whilst participants went on to be assessed longitudinally, only PANSS data collected at baseline were used in this study.

3.3.2. Participants

All individuals included in the current study were participants in the National EDEN study (see section 2.3 for further details). All National EDEN participants with complete baseline PANSS data (n = 967) were included in the current study.

3.3.3. Sample size

There are varying opinions as to the sample size required to successfully conduct factor analysis. A number of rules of thumb, typically stated in terms of minimum sample size or ratio of the sample size to the number of variables analysed, have been proposed. The minimum sample sizes suggested vary considerably but several authors recommend n = 100 as the minimum adequate sample size required (MacCallum, Widaman, Zhang, & Hong, 1999). Comrey & Lee (1992, cited by MacCallum et al., 1999) offered the following guidelines for assessing the adequacy of a sample size for factor analysis: 100 = poor, 200 = fair, 300 = good, 500 = very good, and 1000 or more = excellent. Suggestions as to the necessary ratio of participants to measured variables range from 20:1 at the most conservative to 3:1 at the least. Comprising 967 participants – 32.23 (967/30) participants per measured variable – this study’s sample is large enough for successful factor analysis according to even the more conservative guidelines.

3.3.4. Procedure

Individuals who consented to take part in National EDEN met with a study Research Assistant to complete an assessment as soon as possible following acceptance into a participating EIP Service. Research Assistants were graduates in psychology or another relevant discipline working alongside participating EIP services.

Assessments were conducted at a venue convenient for the participant, for instance the participant’s home, their GP surgery or mental health service base. A large battery of assessment measures was administered in order to address the wide-

ranging research objectives of National EDEN. The PANSS was one of 18 measures administered at baseline.

Steps were taken to ensure adequate inter-rater reliability and guard against rater 'drift' over time (for further details see Birchwood et al., 2014). All Research Assistants were trained in rating the PANSS by experienced members of the study team and were required to demonstrate adequate inter-rater reliability (kappa or intra-class correlation $r > 0.75$) using standardised training videos before being permitted to begin providing ratings for the study. Throughout the study, a proportion of PANSS interviews conducted at each site were rated independently by multiple trained assessors and good inter-rater reliability was observed.

3.3.5. Analysis Plan

All analyses were conducted using Mplus for Windows, Version 7.1 (Muthén & Muthén, 1998 - 2012).

First, score distributions for each PANSS item were examined to check whether assumptions of normality could be justified. Next, EFA with geomin rotation (an oblique rotation which allows for correlation between factors) was conducted. EFA aims to identify the smallest number of unobserved latent factors that can explain the shared variability in a set of observed data. It is a data-driven technique used when the researcher has no a priori theory about the factor structure of a scale. Factor solutions with between three and seven factors were compared on the basis that published factor solutions for the PANSS have retained a minimum of three and maximum of seven factors.

Application of the Kaiser criterion, inspection of a scree plot of the eigenvalues, and parallel analysis were used in conjunction with consideration of the theoretical interpretability of the factors retained in deciding how many factors to retain. Kaiser's criterion (H. Kaiser, 1960) states that only factors with an eigenvalue greater than one should be retained. The eigenvalue of a factor indicates the amount

of variance accounted for by that factor; the lower the eigenvalue the less variance is explained. Since the average eigenvalue for a set of factors will always be one, Kaiser's criterion has the effect of classing all factors that account for greater than average variance as worthy of retention. Whilst this is the most common method of determining the number of factors to retain following EFA (Gaskin & Happell, 2014), reliance on this criterion is now widely discouraged (Courtney, 2013). As discussed by Fabrigar, Wegener, MacCallum, & Strahan (1999), not only is this rule rather arbitrary, several simulation studies have demonstrated that this criterion tends to overestimate the optimal number of factors to retain.

The scree test (Cattell, 1966) involves plotting the eigenvalues of each factor in order of magnitude (from largest to smallest) and visually inspecting the graph to identify the 'elbow': the point at which the last substantial drop in eigenvalues occurs. This method enables the researcher to identify and discard those factors that describe relatively minimal variance relative to other more major factors. However, since there is no clear definition of what constitutes a substantial drop in eigenvalues, the procedure suffers from a high degree of subjectivity when there is not a clear discontinuity in the plot (Courtney, 2013).

Parallel analysis (Horn, 1965) involves plotting the eigenvalues of the sample data alongside the average eigenvalues of a number of random datasets with the same sample size and number of variables. Sample eigenvalues which are greater than the eigenvalues of the random datasets are retained and those which are equal to or smaller than the values for the random data are assumed to be the result of sampling error. Parallel analysis has been argued to be one of the most accurate factor retention methods (Hayton, Allen, & Scarpello, 2004).

CFA was then carried out to determine how well the model created on the basis of the EFA fitted to the observed data. As its name would suggest, CFA is a technique used to confirm the adequacy of a pre-determined factor model; the fit of the model to the data is observed and quantified using fit indices. A wide range of fit indices can be computed and, since each index has advantages and disadvantages, it is

recommended that a range of indices are utilised when making decisions regarding fit adequacy (Hu & Bentler, 1998). The fit indices considered in this study were the Root Mean Square Error of Approximation (RMSEA), Comparative Fit Index (CFI) and Tucker-Lewis Index (TLI). In line with common ‘rules of thumb’, cut-offs for these indices for adequacy of model fit were set a priori at > 0.90 for the CFI and TLI, and < 0.06 for the RMSEA (Marsh, Hau, & Wen, 2004).

Finally, ESEM was conducted. ESEM (Asparouhov & Muthén, 2009) is a method of evaluating the underlying factor structure of a measure which integrates exploratory and confirmatory factor analysis. Unlike CFA, which allows each item to load on only one factor and constrains all other loadings to zero, ESEM allows items to act as indicators of more than one factor. ESEM requires the number of factors to be specified a priori but does not require the researcher to make any decisions about which items indicate which factors. Both the correlation and variance/covariance matrices are analysed in obtaining the solution and the structure obtained with factor rotation. In this study, the choice of the number of factors to specify was guided by the results of the EFA and geomin rotation used to obtain the factor structure. The fit indices considered were those described above. Items with a factor loading of at least 0.3 were used to create a custom negative symptoms subscale.

3.4. RESULTS

Score distributions for all PANSS items were positively skewed. For this reason, an estimator robust to violations of the assumption of normality (maximum likelihood with robust means and variances) was employed in all analyses.

3.4.1. Exploratory and Confirmatory Factor Analysis

EFA with geomin rotation was used to obtain factor solutions with between three and seven factors. Items were allocated to factors according to their highest loading. Six factors had eigenvalues greater than one, suggesting that the six-factor solution should be selected according to the Kaiser criterion. A scree test did not yield a clear result as the plot of eigenvalues (Figure 3.1) was difficult to interpret due to lack of a clear ‘elbow’; however, it would appear to suggest retaining between three and five factors. Parallel analysis conducted with 50 randomly generated datasets indicated that five factors should be retained (also Figure 3.1).

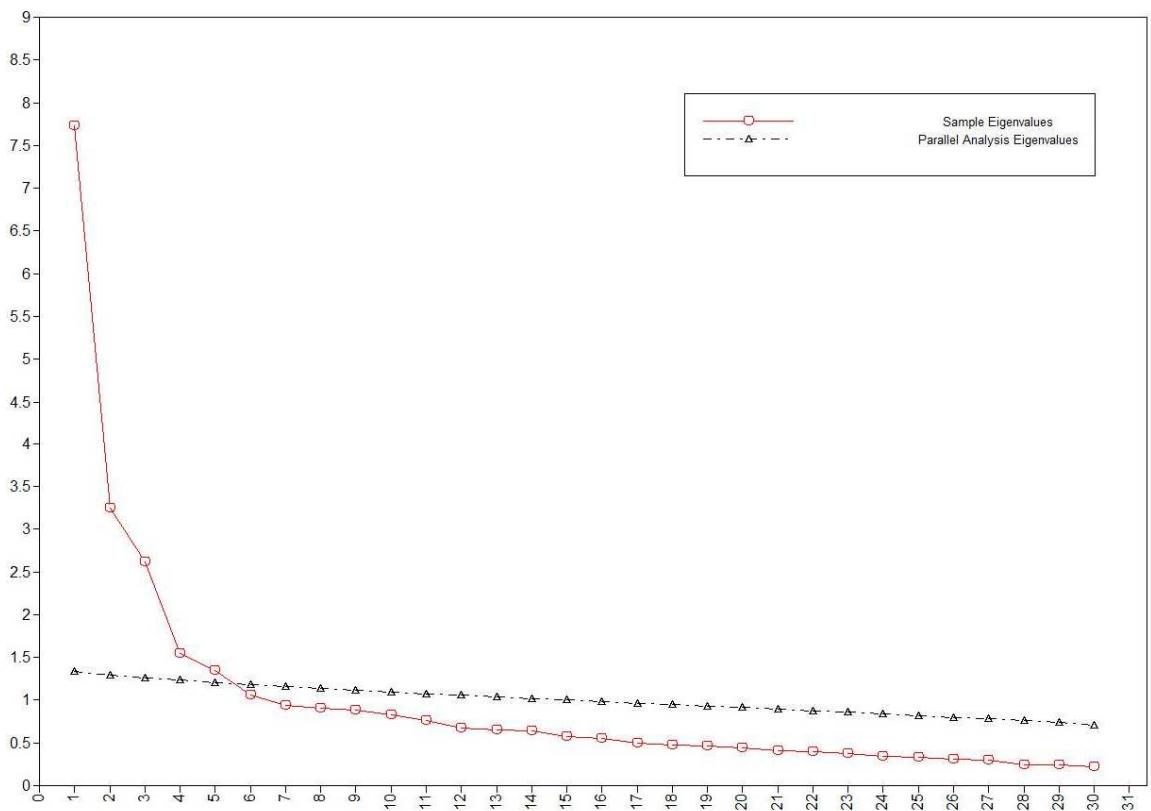


Figure 3.1. Scree plot of sample eigenvalues and parallel eigenvalues for 50 random datasets.

Given the limitations of the Kaiser criterion and good performance of parallel analysis in studies using data with known factor structure (Ruscio & Roche, 2012), the five-factor solution favoured by parallel analysis and in the range suggested by the scree plot was selected over the six-factor solution favoured by the Kaiser criteria. The factors were labelled ‘Negative Symptoms’, ‘Aggression/Hostility’, ‘Disorganisation’, ‘Positive Symptoms’ and ‘Affective Symptoms’. The items which indicate each factor and corresponding factor loadings are presented in Table 3.2.

Table 3.2. Factors and standardised item loadings for EFA with geomin rotation: five-factor solution.

PANSS Items	Factor Loading
<i>Factor 1 – Negative Symptoms</i>	
N1 Blunted affect	0.800
N6 Lack of spontaneity and flow of conversation	0.732
N2 Emotional withdrawal	0.729
N4 Passive social withdrawal	0.707
N3 Poor rapport	0.646
G7 Motor retardation	0.627
<i>Factor 2 – Aggression/Hostility</i>	
P7 Hostility	0.809
G8 Uncooperativeness	0.623
G14 Poor impulse control	0.537
<i>Factor 3 – Disorganisation</i>	
P2 Conceptual disorganisation	0.761
G11 Poor Attention	0.702
G13 Disturbance of volition	0.608
G15 Preoccupation	0.559
P4 Excitement	0.531
N7 Stereotyped thinking	0.437
N5 Abstract thinking	0.359
G5 Mannerisms and posturing	0.363
G10 Disorientation	0.297
<i>Factor 4 – Positive Symptoms</i>	
P1 Delusions	0.800
G9 Unusual thought content	0.690
P6 Suspiciousness/persecution	0.459
P5 Grandiosity	0.363
P3 Hallucinations	0.356
<i>Factor 5 – Affective Symptoms</i>	
G2 Anxiety	0.765
G6 Depression	0.683
G4 Tension	0.583
G3 Guilt feelings	0.411
G16 Active social avoidance	0.391
G12 Lack of judgement and insight	0.319
G1 Somatic concern	0.249

Next, CFA was conducted to determine whether the five-factor model suggested by the EFA fit the data adequately. The CFA suggested unacceptably poor model fit according to all three fit indices calculated ($\text{RMSEA} = 0.079$; $\text{CFI} = 0.752$; $\text{TLI} = 0.727$). Inspection of the factor loadings revealed that several items loaded strongly on more than one factor.

3.4.2. Exploratory Structural Equation Modelling

Since the CFA did not confirm the adequacy of a five-factor model in which all cross-loadings are constrained to zero, ESEM was carried out to determine whether it would be possible to obtain a five-factor model that fit the data adequately by allowing items to load on more than one factor. This approach yielded acceptable model fit according to the majority of indices ($\text{RMSEA} = 0.054$; $\text{CFI} = 0.914$; $\text{TLI} = 0.874$). The factors that resulted and the factor loadings associated with each item are presented in Table 3.3. The factor structure obtained using ESEM corresponded closely with that obtained using EFA and factors were labelled accordingly. Two items – ‘tension’ (G4) and ‘active social avoidance’ (G16) loaded strongly on more than one factor.

Table 3.3. Factors and standardised item loadings for ESEM with geomin rotation (loadings greater than 0.3 retained).

Items Grouped by Factors	Factor Loading
<i>Factor 1 – Negative Symptoms</i>	
N1 Blunted affect	0.800
N6 Lack of spontaneity and flow of conversation	0.732
N2 Emotional withdrawal	0.729
N4 Passive social withdrawal	0.707
N3 Poor rapport	0.646
G7 Motor retardation	0.627
G16 Active social avoidance	0.369
<i>Factor 2 – Aggression/Hostility</i>	
P7 Hostility	0.809
G8 Uncooperativeness	0.623
G14 Poor impulse control	0.537
<i>Factor 3 – Disorganisation</i>	
P2 Conceptual disorganisation	0.761
G11 Poor Attention	0.702
G13 Disturbance of volition	0.608
G15 Preoccupation	0.559
P4 Excitement	0.531
N7 Stereotyped thinking	0.437
G5 Mannerisms and posturing	0.363
N5 Abstract thinking	0.359
G4 Tension	0.324
<i>Factor 4 – Positive Symptoms</i>	
P1 Delusions	0.800
G9 Unusual thought content	0.690
P6 Suspiciousness/persecution	0.459
P5 Grandiosity	0.363
P3 Hallucinations	0.356
G12 Lack of judgement and insight	0.305
<i>Factor 5 – Affective Symptoms</i>	
G2 Anxiety	0.765
G6 Depression	0.683
G4 Tension	0.583
G3 Guilt feelings	0.411
G16 Active social avoidance	0.391

3.5. DISCUSSION

3.5.1. Summary of Findings

Using EFA to explore PANSS data from an FEP sample resulted in a five-factor model. However, this model was found to be an inadequate fit to the data when CFA was employed. By using ESEM a five-factor model was arrived at that fitted the FEP data adequately according to the majority of fit indices. The five factors in this model were labelled ‘Negative Symptoms’, ‘Aggression/Hostility’, ‘Disorganisation’, ‘Positive Symptoms’ and ‘Affective Symptoms’, in line with labels given to PANSS factors with similar indicating items in the literature. Two items loaded strongly on more than one factor, including ‘active social avoidance’ (G16) which loaded on both the Negative Symptoms and Affective Symptoms factors. The factor corresponding to the negative symptoms construct included five items from the negative subscale of the PANSS (‘blunted affect’ (N1), ‘emotional withdrawal’ (N2), ‘poor rapport’ (N3), ‘passive social withdrawal’ (N4), and ‘lack of spontaneity and flow of conversation’ (N6)) and two items from the general subscale (‘motor retardation’ (G7) and ‘active social avoidance’ (G16)).

3.5.2. Interpretation, Relevance to the Literature and Theoretical Significance

In common with previous studies (Fitzgerald et al., 2003; van der Gaag et al., 2006a) the CFA in the present study failed to confirm the adequacy of a five-factor model of the PANSS identified using EFA. As noted by Marsh et al. (2009), failure to confirm a factor structure using CFA is not a problem peculiar to the PANSS but a difficulty encountered by researchers investigating the factor structures of many psychological measurement tools.

Many psychological instruments have an apparently well-defined EFA structure, but cannot be represented adequately within a CFA approach. Typically this is the result of their factor structures not being consistent with the highly restrictive independent clusters model typically used in CFA

studies in which each item is allowed to load on one factor and all non-target loadings are constrained to be zero.

(Marsh et al., 2009; p. 440)

Van den Oord et al. (2006) observe that it is those PANSS items that display substantial cross-loadings that do not consistently appear in the same scale across the literature, and which are often omitted altogether. It might be argued that omitting items with substantial cross-loadings increases discriminant validity, and so should be preferred to employing techniques that allow for cross-loadings. However, this assumes that the cross-loadings observed are the result of items being poorly defined rather than symptoms having multiple possible causes. As van der Gaag et al. (2006b) argue, this is unlikely to be a valid assumption in the case of the PANSS since many of the symptoms it measures have more than one possible cause.

For instance, 'active social avoidance' (G16), rated on the basis of diminished social involvement judged to be due to fear, hostility or distrust, might be the result of asociality, social anxiety, paranoid beliefs, or a combination of all three. Thus, that the current study found this item to load on both the Negative Symptoms and Affective Symptoms factors can be seen to reflect the complex clinical reality of psychosis presentations. To remove this item would be to ignore this complexity, and result in inadequate measurement of the asociality dimension of the negative symptoms construct.

Despite the unconventional method employed, the five factors identified by the current study were in line with those commonly identified in factor analytic studies of the PANSS (Fitzgerald et al., 2003; Wallwork et al., 2012). The factors identified correspond closely to those of other five-factor models including the pentagonal model (White et al., 1997), the consensus model identified by Wallwork et al. (2012), the model identified by Emsley et al. (2003) in an FEP sample, and to the model suggested by van der Gaag et al.'s (2006b) cross-validation study. The five factors are also conceptually similar to those identified by a recently published study that used ESEM to confirm the factor structure of the PANSS in a small sample of Chinese schizophrenia patients (Fong, Ho, Wan, Siu, & Au-Yeung, 2015).

Turning to the Negative Symptoms factor specifically, Liemburg et al. (2013) retrieved all previous factor analytic studies of the PANSS that reported a negative symptom factor ($n = 33$) and listed the items that had been identified as measuring negative symptoms by each of these studies. Of the 30 PANSS items, half were deemed to measure negative symptoms by at least one study. Those items found to indicate the negative factor in the current study were the seven items most commonly identified as negative symptoms: 'blunted affect' (N1), 'emotional withdrawal' (N2), 'poor rapport' (N3), 'passive social withdrawal' (N4), and 'lack of spontaneity and flow of conversation' (N6) were all included as part of the negative symptom factor by at least 31/33 studies, 'motor retardation' (G7) was included by 23/33 and 'active social avoidance' (G16) by 20/33. The next most commonly included item was 'disturbance of volition' (G13); all other items were rarely identified as indicating the negative symptom construct (≤ 5 studies).

A five-factor model was specified in the ESEM for this study based on the results of the EFA. However, had a six-factor model been specified, two negative symptoms factors would have emerged, one indicated by the items 'blunted affect' (N1), 'poor rapport' (N3), 'lack of spontaneity and flow of conversation' (N6) and 'motor retardation' (G7), the other by 'emotional withdrawal' (N2), 'passive social withdrawal' (N4) and 'active social avoidance' (G16) (see Appendix A). The item-assignments of these two factors are identical to those of the 'Negative' and 'Withdrawn' factors in van den Oord et al.'s six-factor model. They also mirror the two factors that emerged when Liemburg et al. (2013) subjected PANSS items related to the negative symptom construct to EFA (in all respects other than the inclusion of 'disturbance of volition' (G13) and 'mannerisms and posturing' (G5) as negative symptoms in Liemburg et al.'s analysis). Whilst negative symptoms are, for the most part, treated as a unitary concept in this thesis, this suggests the potential value of treating negative symptoms as comprising two distinct symptom domains in future FEP research.

3.5.3. Limitations

When interpreting the results of factor analyses, it is important to keep in mind that statistical techniques can only provide information about the mathematical relationship between variables. The results of a factor analysis leave unanswered questions about *why* there is a relationship between variables. Whilst it is hoped that items that load on the same factor do so due to their shared measurement of a latent variable, this cannot be guaranteed. There are a number of other possible explanations for items loading on a shared factor. For instance, in the case of the PANSS, shared methodological variance might be introduced by the fact that certain items are rated on the basis of observations of behaviour whereas other ratings are grounded primarily in the content of responses given to specific questions in the semi-structured interview. This shared methodological variance may result in the greater coherence of items with a similar basis for rating. It is also possible that there may be higher order factor structures (related to systematic differences between raters or study sites for instance) not included in the model. Such higher-order factor structures may also account for the coherence of certain items and for the cross-loadings of items.

If factor analytic techniques are unable to provide firm assurance that items that load on a single factor do so as a result of their measuring a common latent variable, they are still less able to attest the nature of this latent variable. While inferences can be drawn about the latent variable from the items found to indicate it (assuming it is the reason for their shared variance), these inferences must be informed by sound theoretical understanding of the constructs in question. However, in the current study the interpretation of factors was informed by a substantial literature on the structure of psychotic symptomatology and is unlikely to be controversial.

When interpreting the results of this study, it should be kept in mind that it is possible that the EDEN cohort is not representative of the wider FEP population. Of the individuals eligible for inclusion in EDEN during the study period, 51% were unable to be recruited. Whilst participants were demographically similar to non-

participants (Birchwood et al., 2014), it is possible that participants may have differed from non-participants on one or more dimensions not captured by the limited data available on non-participants. For instance it is possible that participants' symptom profiles differed from those of non-participants, which may have influenced the factor structure observed. Since it is possible that a model might fit the data from a non-representative sample well but be a poor fit for a sample drawn randomly from the population, caution must be exercised in generalising the findings beyond this particular sample.

While this study sought to overcome a major limitation of using the PANSS to measure negative symptoms, i.e. the inclusion of items not reflecting negative symptom severity in the negative subscale, the construction of a bespoke negative symptom subscale reflecting the scale's factor structure cannot overcome the limitations of the PANSS altogether. For instance, including the item 'active social avoidance' (G16) in the negative symptom subscale will result in more accurate measurement of negative symptom severity in individuals whose diminished social involvement reflects asociality. However, where an individual presents with diminished social involvement as a result of social anxiety, the inclusion of this item will lead to an artificial inflation of their negative symptoms score. Thus the measurement of negative symptoms in this thesis remains limited.

3.6. CONCLUSION

This study suggests that a five-factor model fits PANSS data from an FEP sample adequately if some items are permitted to load on more than one factor. The five-factor model that emerged incorporated a single negative symptom factor indicated by five items from the negative subscale of the PANSS ('blunted affect' (N1), 'emotional withdrawal' (N2), 'poor rapport' (N3), 'passive social withdrawal' (N4), and 'lack of spontaneity and flow of conversation' (N6)) and two items from the general subscale ('motor retardation' (G7) and 'active social avoidance' (G16)). The mean score of these seven items was thus used to measure negative symptom severity for the purposes of this thesis.

Chapter Four – The Course of Negative Symptoms in First-Episode Psychosis

4.1. BACKGROUND AND RATIONALE

4.1.1. The Heterogeneous Course of Negative Symptoms

Negative symptoms are not a stable trait, as was once thought, but can fluctuate significantly over time, particularly in the early course of psychosis (Edwards, McGorry, Waddell, & Harrigan, 1999; Ventura et al., 2004). However, individuals vary in the stability of their negative symptoms (Kelley, Haas, & van Kammen, 2008) and there is a subgroup of individuals who present with stably elevated negative symptoms through the early course of psychosis (Chang et al., 2011; Norman, Manchanda, Harricharan, & Northcott, 2015). This subgroup is at elevated risk of poor outcomes (Hovington, Bodnar, Joober, Malla, & Lepage, 2012; Mäkinen, Miettunen, Isohanni, & Koponen, 2008) making early identification of this group an important goal in the quest to improve outcomes following FEP.

Estimates of the prevalence of stably elevated negative symptoms in FEP vary considerably across studies. For example, Galderisi et al. (2013) reported that only 6.7% of their sample presented with negative symptoms that persisted for at least 12 months, whereas 51% of Malla et al.’s (2004) sample were reported to exhibit elevated negative symptoms for 12 months or more. These discrepancies are likely caused, at least in part, by the lack of consensus among researchers and clinicians as to how enduring negative symptoms should be defined. Edwards et al. (1999) and Hovington et al. (2012) compared criteria for defining enduring negative symptoms and both found that the proportion of their FEP samples classed as having enduring negative symptoms varied dramatically depending on the criteria employed.

The ‘deficit syndrome’ criteria (Carpenter, Heinrichs, & Alphs, 1985; Kirkpatrick, Buchanan, Alphs, Carpenter, & Mckenney, 1989) are perhaps the most influential criteria for categorising individuals according to the persistence of their negative symptoms. An individual is categorised as a deficit syndrome patient if he or she: (1)

has been given a diagnosis of schizophrenia, (2) has presented with at least two negative symptoms continuously during all periods of clinical stability over the previous 12 months, and (3) these symptoms were not secondary to other factors. Individuals who meet these criteria have been found to differ from non-deficit patients in their course of illness, biological correlates and treatment response, and these differences have been used to justify the assertion that the deficit syndrome reflects a distinct disease within the schizophrenia syndrome (Kirkpatrick, Buchanan, Ross, & Carpenter, 2001). However, it is unclear that these differences are indicative of a distinct subtype of schizophrenia rather than simply the extreme end of a continuum of negative symptom severity (S. Kaiser, Heekeren, & Simon, 2011).

Evidence in support of a categorical approach to negative symptoms was provided by Blanchard et al. (2005) who used taxonomic statistical techniques to assess whether those with elevated negative symptoms form a distinct latent class. The study supported the existence of a discrete taxon of individuals with elevated negative symptoms within a schizophrenia sample. Individuals in this class were more likely to be males than those not in the class, and demonstrated poorer social functioning. The authors interpreted their findings as providing empirical evidence for the existence of a discrete class of deficit syndrome patients. However, the study did not examine the degree of overlap between membership of the elevated negative symptoms taxon and deficit syndrome classification. As such, Blanchard et al.'s study can only serve as evidence for the validity of a categorical approach to negative symptoms in general, not for the validity of the deficit syndrome approach specifically.

Although the deficit syndrome criteria have been applied to FEP samples, there is evidence that deficit syndrome status assessed soon after psychosis onset is not an accurate predictor of subsequent negative symptom persistence. Subotnik et al. (1998) assessed the stability of deficit symptoms in early psychosis over a 12 month period. Although deficit status at baseline was found to be associated with persistence of negative symptoms over the subsequent 12 months, this association was accounted for primarily by stability of negative symptom absence; participants

classified as non-deficit rarely went on to develop negative symptoms. However, only 40% of those classified as deficit patients at baseline went on to present with stably elevated negative symptoms over the next 12 months. This finding calls into question the validity of the deficit syndrome criteria when applied to FEP.

An alternative means of identifying a distinct subgroup of psychosis patients with enduring negative symptoms is offered by the criteria for 'persistent negative symptoms' (Buchanan, 2007). Persistent negative symptoms are defined as those that: (1) persist for a minimum of 6 months despite usual treatment, (2) interfere with the ability of the patient to perform normal role functions, (3) persist during periods of clinical stability, and (4) represent an unmet clinical need. Unlike the deficit syndrome however, there is no requirement for the negative symptoms to be primary and the severity of symptoms is defined in relation to their impact on functioning. Unfortunately, as these criteria have not been operationalised in a consistent manner, the determination of whether an individual fits into the persistent negative symptoms category is largely dependent on the cut-off points chosen by the classifier. Further, since these criteria require the severity of symptoms to be defined in relation to their impact on functioning, any study looking at the relative functioning of this group in relation to those without persistent negative symptoms would encounter problems of tautology.

Given the lack of consensus regarding how enduring negative symptoms should be defined in FEP, a preferable approach might be to identify clusters of individuals with distinct patterns of longitudinal change in negative symptom severity via an empirically driven approach. Chen et al. (2013) employed such a data-driven approach – Growth Mixture Modelling (GMM; Muthén & Muthén, 2000) – to cluster a sample of individuals with non-affective psychosis according to their pattern of negative symptom change over a 49 week period. Whereas conventional growth modelling techniques assume all individuals change in the same way over time, GMM allows that individuals within a sample might vary in their starting point, rate and direction of change (Jung & Wickrama, 2008). This inter-individual variation is captured by the inclusion of multiple growth curves within the model. The number of growth curves is not specified a priori but is determined using

measures of statistical fit in combination with considerations such as parsimony and theoretical justification.

Chen et al. identified four distinct negative symptom trajectories within their sample: (1) reduction in negative symptoms over the first few weeks followed by a sustained low level of negative symptoms, (2) relatively low negative symptom severity throughout the study period, (3) initially high levels of negative symptoms followed by gradual reduction in severity throughout the study period, and (4) sustained high levels of negative symptoms throughout the study period. The most common trajectory was stably low negative symptoms (accounting for 71% of the sample); the least common trajectory (followed by only 2% of the sample) was gradual reduction in negative symptoms. A trajectory of persistently elevated negative symptoms was characteristic of 16% of the sample.

Chen et al.'s sample consisted of participants in a RCT of antipsychotic medication, a group unlikely to be representative of the wider population of individuals experiencing psychosis. Further, their sample had, on average, experienced 6.4 psychiatric hospitalisations and been ill for more than 17 years. As such, their findings cannot be generalised to individuals early in the course of a psychotic disorder. It is not yet known whether multiple distinct negative symptom trajectories are similarly evident in FEP. If latent classes of individuals with similar negative symptom courses could be identified in an FEP sample, examining predictors of membership of these latent classes may help inform models of negative symptom maintenance in FEP and perhaps facilitate targeted monitoring and intervention.

The current study used Latent Class Growth Analysis (LCGA; Nagin, 1999; 2005) to identify distinct trajectories of change in negative symptom severity in a cohort of individuals with FEP. LCGA is a statistical technique used to identify homogenous sub-groups (latent classes) of individuals with distinct patterns of change over time (Andruff, Carraro, Thompson, & Gaudreau, 2009). LCGA is a subtype of GMM which fixes within-class variation to zero on the assumption that all individuals within a latent class can be modelled by a single trajectory. It is therefore well suited

to investigating whether distinct trajectories of negative symptoms are evident during the early course of psychosis.

4.1.2. Predictors of Negative Symptom Course

Despite variability in their definition, there has been some agreement as to the variables associated with enduring negative symptoms in FEP. The variables explored as possible predictors of negative symptom trajectories in the current study were guided by this literature, but ultimately constrained by the data available within the National EDEN dataset. As such, this section does not seek to provide a comprehensive overview of those factors associated with negative symptom course, but to justify the inclusion of the variables considered as predictors.

Poor premorbid adjustment has been linked with persistence of negative symptoms by several research groups. Bailer et al. (1996) reported an association between premorbid adjustment and the three year course of negative symptoms following a first admission to hospital for non-affective psychosis. They found that those with the poorest premorbid adjustment had persistently higher levels of negative symptoms across all follow-up points than those with better premorbid adjustment. Malla et al. (2004) found that FEP patients whose negative symptoms persisted over the course of 12 months had worse premorbid adjustment during early and late adolescence than did those patients whose negative symptoms had remitted within 12 months. Similarly, Chang et al. (2011) found poor premorbid academic functioning to be the best predictor of persistent negative symptom status three years after it was first assessed in a sample of FEP participants. Evensen et al. (2012) found that stability of blunted affect over a 10 year period following onset of psychosis was best predicted by poor premorbid social functioning.

There is good evidence of a relationship between duration of untreated psychosis (DUP) (the time between the emergence of psychotic symptoms and commencement of antipsychotic medication) and cross-sectional negative symptom severity (Boonstra et al., 2012). The relationship between DUP and negative symptom

persistence over time has been less frequently studied. However, Galderisi et al. (2013) found that longer DUP predicted which of the FEP patients in their sample who presented with at least one negative symptom at baseline would continue to do so one year later. Likewise, Chang et al. (2011) studied persistence of primary negative symptoms over a three year period and found prolonged DUP to predict negative symptom persistence.

Family history of non-affective psychosis, but not other psychiatric disorders, has been found to be associated with persistent negative symptoms in established schizophrenia (Dollfus, Ribeyre, & Petit, 1996; Kirkpatrick, Castle, Murray, & Carpenter, 2000). Male gender has been associated with persistent negative symptoms both in schizophrenia patients (Bottlender, Jäger, Groll, Strauss, & Möller, 2001; Roy, Maziade, Labbé, & Mérlette, 2001), FEP patients (Chang et al., 2011), and also in a non-clinical sample (Maric, Krabbendam, Vollebergh, de Graaf, & van Os, 2003). Additionally, Galderisi et al. (2013) found that FEP patients given a diagnosis of schizophrenia were more likely to experience persistent negative symptoms than those given other diagnoses.

Whilst a positive association has been observed between negative symptoms severity and depression in individuals given a diagnosis of schizophrenia (Kulhara et al., 1989; Sax et al., 1996), Oosthuizen et al. (2002) found an inverse correlation between baseline depression and negative symptom severity in those with FEP. A meta-analysis has confirmed the association between not using substances and cross-sectional negative symptom severity (Potvin, Sepehry, & Stip, 2006). Further, the association between deficit syndrome classification and less severe lifetime use of alcohol, cannabis and other drugs (Kirkpatrick et al., 1996) suggests there may be a relationship between not using substances and negative symptom persistence.

4.2. RESEARCH QUESTIONS

1. Are distinct trajectories of negative symptoms evident during the first 12 months of treatment for FEP?
2. What factors predict the trajectory an individual's negative symptoms will take during the first 12 months of treatment for FEP?

4.3. METHOD

4.3.1. Design

This study has a longitudinal design with participants having been assessed at three time points: on entry into the study (baseline), and six and twelve months later. Negative symptoms were assessed at all three time points using the PANSS. Premorbid adjustment, DUP, past and current substance use, and depression were assessed at baseline. Family history of non-affective psychosis, age at onset, demographic information and baseline clinical diagnosis were ascertained at baseline via participant report and/or case note review.

4.3.2. Participants

The participants were recruited as part of the National EDEN study as described in the previous chapter (section 3.3.2). All those participants who were assessed using the PANSS at one time point or more ($n = 1006$) were included in the current study.

4.3.3. Sample Size

4.3.3.1. Latent Growth Modelling and Latent Class Growth Analysis

Accurately determining an adequate sample size for Latent Growth Modelling (LGM) is difficult due to the relevance of factors such as the amount of variance explained by the model, however sample sizes of at least 100 are often preferred (Curran, Obeidat, & Losardo, 2010). Similarly, although it is believed that small sample sizes limit analysis power and reduce the number of trajectories that can be identified (Andruff et al., 2009), determining adequate sample sizes for LCGA requires a Monte Carlo simulation study (L. K. Muthén & Muthén, 2002). Nagin (2005), who developed LCGA, suggested that a minimum of 300-500 participants are required to successfully conduct LCGA. Given that this study's sample size ($n = 1006$) comfortably exceeds the higher limit of this estimate, it is likely to be adequate for successful use of this analytic technique.

4.3.3.2. One-Way Analysis of Variance (ANOVA)

A power calculation carried out using G*Power Version 3.1.9.2 (Faul, Erdfelder, Lang, & Buchner, 2007) found that to achieve 90% power with a significance level of 0.05, an estimated medium effect size and four comparison groups a minimum sample size of 232 would be required. As such, the one-way ANOVAs conducted were adequately powered.

4.3.3.2. Multinomial Regression

There is not a clear consensus regarding the sample size requirements for multinomial regression. Heuristics for determining an adequate sample size for multinomial logistic regression suggest a minimum of 10 cases per independent variable (Starkweather & Moske, 2011). Since there were twelve candidate explanatory variables, if the maximum number of explanatory variables had been

entered into the multinomial regression model this heuristic would suggest a minimum sample size of 120 participants. However, a simulation study by Taylor et al. (2006) investigating the minimum sample size needed to achieve 80% power in logistic regression models with different numbers of categories suggests that this may be an underestimate. They found that where the underlying distribution is skewed (to take the most conservative estimate), a model with three categories would require 461 cases and a model with five categories 377. These findings provide reasonable confidence that the multinomial regression conducted in this study was adequately powered.

4.3.4. Procedure

The procedures were as described in the previous chapter (section 3.3.4). In addition to the eighteen measures administered at baseline, nine were measured at 6 months, and thirteen at 12 months; a mixture of self-reports, interviewer rated instruments, and clinician completed measures. Data was also extracted from clinical notes. The subset of National EDEN measures included in the current study is described in the next section.

4.3.5. Measures

4.3.5.1. Positive and Negative Syndrome Scale (Kay, Fiszbein, & Opler, 1987)

The PANSS was used to provide a measure of negative symptom severity. The PANSS is a 30-item instrument designed to assess the severity of symptoms associated with schizophrenia. The mean score of seven PANSS items – ‘blunted affect’ (N1), ‘emotional withdrawal’ (N2), ‘poor rapport’ (N3), ‘passive social withdrawal’ (N4), and ‘lack of spontaneity and flow of conversation’ (N6), ‘motor retardation’ (G7) and ‘active social avoidance’ (G16) – was used as the measure of negative symptoms in this study. A detailed explanation of the rationale for the use of these PANSS items to measure negative symptoms was provided in the previous chapter.

4.3.5.2. Duration of Untreated Psychosis (Larsen, McGlashan, & Moe, 1996)

In line with the method described by Larsen et al. (1996), DUP was defined as the interval between onset of frank psychosis and commencement of criterion treatment. Psychosis onset was defined as the first point at which the participant meets criteria for a rating of 4 (moderate severity) on one or more of the items from the PANSS Positive subscale; this rating must be sustained for a period 2 weeks or more (unless remission of symptoms is attributed to commencement of medication). Criterion treatment was defined as adherence to antipsychotic medication prescribed at a dose deemed to be therapeutic for psychosis. Information required to assess the length of this interval was acquired using the PANSS interview, the 'Pathways to Care' interview which systematically questioned the participant about services accessed, presenting problems, treatments offered and duration of treatment received, and by accessing information recorded in clinical notes. Continuous data were dichotomised for the purposes of this study: participants with a DUP of nine months or longer were coded as having a long DUP; participants with a DUP shorter than nine months were coded as having a short DUP. This decision was made because of the non-linear relationship between DUP and negative symptoms such that there is a clear association between DUP and negative symptoms where DUP is less than 9 months but not where it exceeds 9 months (Boonstra et al., 2012).

4.3.5.3. Premorbid Adjustment Scale (PAS; Cannon-Spoor, Potkin, & Wyatt, 1982)

Adjustment prior to the onset of psychosis was assessed using the PAS. The PAS is a retrospective measure of the extent of achievement of key developmental goals during childhood (up to 11 years), early adolescence (11-15 years), late adolescence (16-18 years), and adulthood (19 years and above). Four domains are assessed: sociability and withdrawal, peer relationships, scholastic ability and adaption, and capacity to form intimate sexual relationships (capacity to form sexual relationships is not assessed for the childhood period and scholastic ability and adaption is not

assessed for the adulthood period). Age appropriate functioning in each domain is rated by the researcher on a 7-point scale with 0 denoting optimal adjustment in that domain (no problems with functioning) and 6 denoting the worst adjustment (major problems functioning).

Ratings were based on information obtained during an interview with the participant and corroborated by information from family members where appropriate. Scores for each of the four subscales were calculated by dividing the total score obtained by the participant on that subscale by the total possible score. Since around a third of the national EDEN sample experienced onset of their psychosis before the age of 19, only adjustment in childhood and early adolescence was considered in this study to reduce the risk of confounding with early psychosis onset.

4.3.5.4. DrugCheck (Kavanagh et al., 1999)

The DrugCheck is an interviewer-administered instrument designed to screen for substance misuse disorders in people with psychosis. The interviewer asks the participant about the frequency of their drug use over the previous 3 months and, if relevant, gains an estimate of the quantity used. The instrument also includes a 13-item problem list that assessed the functional impact of the most problematic substance. In addition, participants in National EDEN were asked about their past use of substances. For the purposes of the current study, baseline substance misuse was coded as present if the participant reported lifetime use of any illicit substance.

4.3.5.5. Calgary Depression Scale for Schizophrenia (CDSS; Addington, Addington, Matickayndale, & Maticka-Tyndale, 1994)

The CDSS was used to measure severity of depression. The CDSS is a 9-item scale rated by a trained interviewer on the basis of observation and a semi-structured interview with the participant. Each item is rated according to operational criteria on a 4-point scale. The CDSS depression score is calculated by summing each of the 9 item scores; higher scores represent more severe depression. An important advantage

of the CDSS over other measures of depression severity is that, because it was developed specifically to assess depression in individuals experiencing psychosis, it is designed to minimise overlap with negative symptoms. The specificity of the CDSS has been confirmed empirically (Addington et al., 1994).

4.3.6. Analysis Plan

Analyses were conducted using SPSS for Windows, Version 22 (IBM, 2013) and Mplus for Windows, Version 7.1 (Muthén & Muthén, 1998 – 2012).

4.3.6.1. Preliminary Analysis and Treatment of Missing Data

First, descriptive statistics were calculated for all measures and the distributions of each variable were examined to check whether assumptions of normality are justified. Patterns of missing data were examined to determine whether the assumption that data is missing at random is justified.

Missing data were estimated using full information maximum likelihood (FIML) under the assumption that missing data were missing at random. FIML is a technique for modelling missing data which takes into account all available information by identifying and utilising patterns of missingness. All data, including from participants with incomplete data, are used in estimating parameters. These parameters, together with information on the number of complete data points for each participant, and the observed data at complete time points, are used in the computation of likelihood functions which are maximised across the sample. FIML is considered preferable to alternative procedures for dealing with missing data (Enders & Bandalos, 2001): unlike deletion techniques, FIML makes use of all available data in creating the model but unlike imputation techniques (e.g. mean imputation, similar response pattern imputation) it avoids analysing estimated values as if they were observed.

4.3.6.2. Research Question 1: Are distinct trajectories of negative symptoms evident during the 12 months following initiation of treatment for FEP?

In order to examine the pattern of negative symptom change in the sample as a whole and the degree of inter-individual variability in negative symptom course, LGM was carried out prior to beginning LCGA. LGM involves fitting a single trajectory with random effects (representing individual differences) to the data. The mean intercept and slope describe the pattern of change across the whole cohort. Next, LCGA (see section 4.1.1 for discussion of the suitability of this technique) was employed to determine whether variability in individual trajectories is better modelled by multiple, homogenous latent classes with distinct trajectories, than by a single trajectory. Models with increasing numbers of latent classes were fitted to the data and the best model selected according to a number of considerations including goodness of fit to the data, entropy, specificity of posterior probabilities, parsimony and interpretability (Jung & Wickrama, 2008).

Since there is no consensus on the best criteria for determining the relative fit of models with different numbers of classes (Nylund, Asparouhov, & Muthén, 2007), four indices were used in tandem to assess statistical fit. The fit indices considered were Akaike's Information Criterion (AIC), Bayesian Information Criterion (BIC), Bootstrap Likelihood Ratio Test (BLRT) and Lo–Mendell–Rubin Likelihood Ratio Test (LMR-LRT). These fit indices give an indication of relative, but not absolute, model fit. Lower AIC and BIC values indicate superior fit: given any two models, the model with the lower IC value should be preferred. A significant BLRT or LMR-LRT value is indicative of the model being a better fit than the model with one fewer latent classes. Entropy is a measure of how distinct each of the latent classes is from the other classes in the model. Entropy values range from 0 to 1, with values close to 1 indicating a high degree of distinctness. The mean posterior probabilities of an individual belonging to a latent class indicate the probability of a model allocating an individual to the 'true' class. Good models should have classes with mean posterior probabilities close to 1 (probabilities greater than 0.7 can be considered adequate; Andruff et al., 2009), indicating a high probability of belonging to just one class.

4.3.6.3. Research Question 2: What factors predict the trajectory an individual's negative symptoms will take during the 12 months following initiation of treatment for FEP?

To address the second research question, the latent classes resulting from the selected model were compared on demographic and baseline variables hypothesised to be associated with negative symptom course. There were twelve candidate exploratory variables: age at psychosis onset; gender; ethnicity; family history of non-affective psychosis; schizophrenia diagnosis; DUP; premorbid social adjustment in childhood; premorbid social adjustment in adolescence; premorbid academic adjustment in childhood; premorbid academic adjustment in adolescence; baseline depression; and history of substance use. A two-step process was employed to reduce the risk of overfitting the regression model. First, a series of univariate between class comparisons were conducted and only those variables that differed significantly were entered into the multinomial regression examining predictors of negative symptom course.

In the case of continuous variables, differences between classes were examined using one-way ANOVAs. Due to the use of multiple comparisons, the Bonferroni correction was used to adjust the critical p-value ($0.05/7 = 0.007$) to minimise the risk of Type I errors. Where an ANOVA identified a significant main effect, post-hoc Turkey's HSD tests were used to examine which classes differ significantly. In the case of categorical variables, Person's Chi-Squared tests were used to assess associations with negative symptom class. Fisher's Exact Test was used to calculate the p value where expected values were small (< 5) in the case of 20% or more of the cells. Where a significant association was found, the adjusted standardised residuals of the Chi-squared test were examined to establish which of the latent classes were over- or under-represented. Variables that differed significantly between latent classes were entered into a multinomial regression model with latent class as the dependent variable.

4.4. RESULTS

4.4.1. Sample Characteristics and Descriptive Data

Information on the demographic and baseline clinical characteristics of the participants included in the present study ($n = 1006$) are presented in Table 4.1. There were significantly more men than women ($\chi^2 (1) = 146.58$, $p = <0.001$) and significantly more participants identified their ethnicity as White British than any other ethnicity ($\chi^2 (14) = 6656.67$, $p = <0.001$). The majority of participants (72%) received a clinical diagnosis of ‘Unspecified Psychosis’ at baseline. This is in line with the underlying philosophy of EIP services which encourages embracing early diagnostic uncertainty and allowing sufficient time for symptoms to stabilise before a diagnosis is made (Department of Health, 2001). Descriptive statistics for continuous baseline variables included in the analysis are given in Table 4.2.

Table 4.1. Characteristics of participants included in the current study ($n = 1006$).

	Sample Characteristics
Age at Onset – Mean (SD)	20.07 (7.78)
Gender (% Male)	69.1
Ethnicity (%)	
White British	70.3
Asian	15.5
Black	6.8
Mixed	4.2
Other	3.3
Family History of Non-Affective Psychosis (%)	8.9
Initial Clinical Diagnosis (%)	
Unspecified Psychosis	72.0
Schizophrenia	10.6
Bipolar	5.2
Drug Induced Psychosis	6.7
Paranoid Psychosis	3.7
Schizoaffective Disorder	1.7

Table 4.2. Descriptive statistics for continuous baseline variables included in the current study.

	Mean (SD)	Skewness
PANSS Negative Symptoms Mean	2.16 (1.00)	0.86*
PAS Social – Childhood	0.20 (0.21)	0.87*
PAS Social – Adolescence	0.23 (0.19)	0.89*
PAS Academic – Childhood	0.26 (0.21)	0.66*
PAS Academic – Adolescence	0.36 (0.24)	0.32*
Calgary Depression	6.30 (5.38)	0.77*

Notes. 'PANSS Negative Symptoms' refer to the items used to measure negative symptom severity in the current study as opposed to the original negative subscale.

* = The distribution of the variable deviates significantly from normality (Komolgorov-Smirnov test for normality yielded a p-value ≤ 0.05)

The distribution of all continuous baseline variables were explored using visual inspection of histograms and P-P plots in conjunction with Komolgorov-Smirnov tests. All variables were found to be positively skewed. Non-normality was accounted for in the latent growth modelling and latent class growth analysis by use of an estimator robust to violations of the assumption of normality (maximum likelihood with robust means and variances). Simulation studies have demonstrated the ANOVA to be robust to minor violations of normality in large samples (Harwell, Rubinstein, Hayes, & Olds, 1992). Whilst moderately skewed distributions can lead to reductions in statistical power, given the current study's relatively large sample size this was judged to be unlikely to pose significant problems.

4.4.2. Missing Data

Of the participants in National EDEN, 98.0% (1006) had complete PANSS data for at least one time point and were therefore included in the current study. There was no difference between those who did and did not have PANSS data at one time point or more in terms of gender ($\chi^2 (1) = 0.056$, $p = 0.812$), age at onset of psychosis ($t (981)$

= -0.109, $p = 0.913$), ethnicity (Fisher's Exact Test, $p = 0.426$), or family history of non-affective psychosis (Fisher's Exact Test, $p = 1.000$). This suggests that the participants included in this study are likely to be representative of the National EDEN cohort as a whole.

Of the 1006 participants included in the current study, 63.4% had complete PANSS data at all three time points and 85.7% had complete PANSS data at two time points or more. There was a significant main effect of number of time points with complete PANSS data on baseline average negative symptom score ($F (2) = 4.885$, $p = 0.008$). Post-hoc comparisons using Tukey's HSD test indicated that those with complete PANSS data at all three time points had significantly higher levels of negative symptoms at baseline than those with data at only two time points. There were no significant differences in the baseline negative symptoms of those with complete data at three versus one, or two versus one time point. The ramifications of the relationship between missingness and negative symptom severity will be considered in the limitations section at the end of this chapter (section 4.5.3).

4.4.3. Latent Growth Modelling and Latent Class Growth Analysis

Prior to examining models with multiple latent classes, a single-class latent growth model was specified. The unstandardised mean intercept was 2.08 ($p = <0.001$) and the unstandardised mean slope was -0.21 ($p = <0.001$), indicating that negative symptoms tended to decrease over time in the sample as a whole. However, this model fitted the data poorly ($RMSEA = 0.193$, $CFI = 0.887$, $TLI = 0.661$). Notably, there was significant variance in both the slope (estimated variance = 0.085, $p = 0.001$) and intercept (estimated variance = 0.450, $p = <0.001$) of the estimated growth curve, suggesting that the negative symptom trajectories followed by the sample are not homogeneous.

LCGA was then applied to examine models of negative symptom change incorporating multiple trajectories. Beginning with a model with two latent classes, models with increasing numbers of latent classes were specified. Fit indices, entropy,

accuracy of posterior classifications, and the size of each class were compared for each of the alternative models, as presented in Table 4.3. The model with four latent classes was selected from the models considered. This model fit the data significantly better than the models with one, two and three latent classes according to all fit indices (ICs for single-class latent growth model: AIC = 6007.67, BIC = 6046.98). Further, each of the four latent classes represented a distinct symptom trajectory with significant theoretical relevance. Mean posterior probabilities for all four latent classes are adequately high (> 0.70), indicating high probability of classification to the correct latent class. Further, no latent class is made up of less than 5% of the sample, indicating that each trajectory characterises a substantial subgroup of the sample.

Whilst models with five classes fit the data significantly better than the four-class model according to all fit indices other than the LMR-LRT, this model was not preferred for reasons of parsimony and interpretability. As the number of latent classes increased, the two Information Criteria continued to decrease: no stagnation or reverse in the direction of change was observed. However, models with more than four latent classes increasingly included classes comprising less than 5% of the sample and which did not represent a sufficiently unique and distinct trajectory to be easily interpretable.

Table 4.3. Comparison of LCGA models with two to six latent classes.

	2	3	4	5	6
AIC	5893.21	5740.96	5639.24	5564.28	5464.70
BIC	5932.52	5795.01	5708.03	5647.81	5562.98
BLRT	0.00	0.00	0.00	0.00	0.00
LMR-LRT	0.00	0.06	0.03	0.13	0.06
Entropy	0.83	0.81	0.79	0.79	0.79
Classification Probabilities	0.96, 0.90 0.94, 0.89	0.84, 0.94, 0.89	0.84, 0.92, 0.91, 0.79	0.89, 0.77, 0.91, 0.83, 0.80	0.83, 0.76, 0.91, 0.84, 0.88, 0.87
Class Size (%)	81, 19	21, 74, 5	14, 64, 5, 17	3, 17, 64, 11, 5	15, 14, 3, 7, 57, 3

Note. AIC = Akaike's Information Criterion, BIC = Bayesian Information Criterion, BLRT = Bootstrap Likelihood Ratio Test, LMR-LRT = Lo–Mendell–Rubin Likelihood Ratio Test. Classification Probabilities = mean posterior probabilities for each class, Class Size = proportion of the sample making up the membership of each class.

4.4.4. Description of Latent Classes

Modal assignment was used to allocate participants to latent classes, that is, estimates of the posterior probabilities of each participant belonging to each of the latent classes were calculated and the participant assigned to the class with the highest posterior probability. The characteristics of each latent class were as follows. The model is presented graphically in Figure 4.1.

Class 1 – ‘Mild Stable’ Negative Symptoms The first class contained 13.5% of the sample ($n = 108$). It was characterised by an intercept corresponding to elevated negative symptoms (unstandardised mean intercept = 2.185) and a non-significant slope (unstandardised mean slope = 0.237, $p = 0.080$) indicating stable mild negative symptoms.

Class 2 – ‘Minimal Decreasing’ Negative Symptoms The second class comprised the majority of the sample (63.9%, $n = 674$). This class was characterised by a low intercept (unstandardised mean intercept = 1.620), indicating minimal levels of

negative symptoms at baseline. These negative symptoms decreased slightly but significantly over time (unstandardised mean slope = -0.166, $p = <0.001$).

Class 3 – ‘High Stable’ Negative Symptoms The third class contained the fewest participants (5.4%, $n = 50$). This class had the highest mean intercept (unstandardised mean intercept = 3.581) and a non-significant slope (unstandardised mean slope = 0.053, $p = 0.696$), indicating persistently high levels of negative symptoms.

Class 4 – ‘High Decreasing’ Negative Symptoms The final class contained 17.1% of the sample ($n = 174$). The class are characterised by an intercept comparable to the High Stable class (unstandardised mean intercept = 3.351) indicating high levels of negative symptoms at baseline. However, this class’ symptoms decreased significantly over time (unstandardised mean slope = -0.890, $p = <0.001$), realising a level similar to the ‘Minimal Decreasing’ class by 12 months.

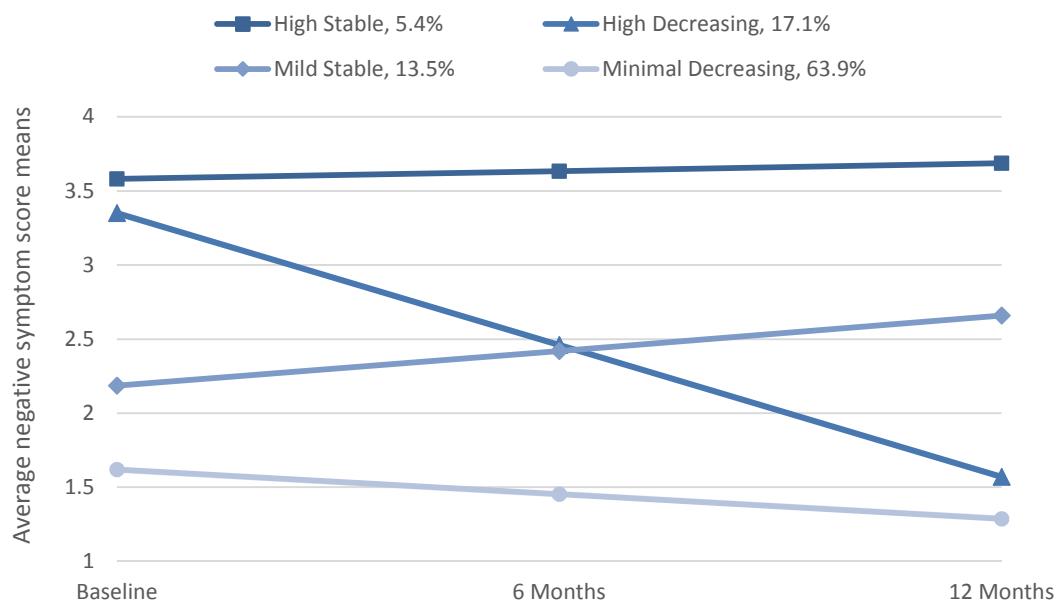


Figure 4.1. LCGA with four latent classes: average negative symptom score estimated means.

4.4.5. Between Class Differences

The four negative symptom trajectory classes were compared on demographic and baseline variables. Descriptive statistics for each class are presented in Table 4.4. Class differences were found in gender ($\chi^2 (3) = 9.253$, $p = 0.026$), baseline clinical diagnosis (Fisher's Exact Test, $p = 0.019$), family history of non-affective psychosis (Fisher's Exact Test, $p = 0.001$), premorbid social adjustment in childhood ($F (3, 904) = 5.116$, $p = 0.002$) and early adolescence ($F (3, 864) = 7.240$, $p = <0.001$), premorbid academic adjustment in childhood ($F (3, 904) = 7.270$, $p = <0.001$) and early adolescence ($F (3, 899) = 10.236$, $p = <0.001$), and baseline depression ($F (3, 943) = 11.285$, $p = <0.001$). No significant class differences were found in age at onset ($F (3, 1002) = 1.094$, $p = 0.351$), ethnicity (Fisher's Exact Test, $p = 0.096$), DUP ($\chi^2 (3) = 0.837$, $p = 0.841$) or illicit substance use ($\chi^2 (3) = 3.388$, $p = 0.336$).

Table 4.4. Descriptive statistics (mean (SD) unless otherwise indicated) for each negative symptom trajectory class.

	Minimal Decreasing (n = 674)	Mild Stable (n = 108)	High Decreasing (n = 174)	High Stable (n = 50)
Age at Onset	19.99 (8.45)	20.65 (5.27)	20.48 (6.54)	18.46 (6.78)
Male Gender	66.9%	77.8%	68.4%	82.0%
White British Ethnicity	70.9%	68.5%	72.4%	58.0%
Family History	6.9%	9.4%	11.5%	25.5%
Schizophrenia Diagnosis	9.8%	10.8%	9.6%	23.4%
DUP \geq 9 months	27.8%	31.8%	28.3%	26.0%
PAS Social - Childhood	0.19 (0.20)	0.25 (0.25)	0.17 (0.19)	0.27 (0.21)
PAS Social - Adolescence	0.21 (0.18)	0.26 (0.23)	0.26 (0.21)	0.31 (0.17)
PAS Acad. - Childhood	0.24 (0.21)	0.34 (0.21)	0.26 (0.19)	0.31 (0.21)
PAS Acad. - Adolescence	0.33 (0.24)	0.45 (0.24)	0.41 (0.25)	0.41 (0.21)
Calgary Depression	5.61 (5.03)	7.36 (5.62)	8.04 (5.66)	6.86 (6.60)
Substance Use	66.3%	63.2%	68.5%	55.1%

Note. Family History = Family History of Non-Affective Psychosis; DUP = Duration of Untreated Psychosis; PAS = Premorbid Adjustment Scale; Acad. = Academic

The Minimal Decreasing class were less likely to have a family history of non-affective psychosis and more likely to have a diagnosis of bipolar or schizoaffective disorder. This class had better premorbid adjustment than members of other classes and were significantly less depressed. The High Decreasing class were less likely to be diagnosed with bipolar disorder and had better premorbid social adjustment during childhood than the High Stable class, but worse social adjustment than the Minimal Decreasing class during adolescence. Members of the Mild Stable class were more likely to be male, had poorer premorbid adjustment, and were more depressed relative to the Minimal Decreasing class. The High Stable class were also

more likely to be male and had poorer premorbid adjustment, as well as a family history of non-affective psychosis and diagnosis of schizophrenia.

An additional post hoc analysis was conducted to investigate whether trajectory classes differed in the profile of negative symptoms exhibited: specifically, if classes differed in the relative prevalence of expressive deficit symptoms (as indicated by the items ‘blunted affect’, ‘poor rapport’, ‘lack of spontaneity and flow of conversation’ and ‘motor retardation’) versus withdrawal symptoms (indicated by the items ‘emotional withdrawal’, ‘passive social withdrawal’, and ‘active social avoidance’). The choice of these items to measure expressive deficit and withdrawal domains of negative symptoms was discussed in section 3.5.2. Mean average expressive deficit and withdrawal symptoms scores by negative symptom trajectory group at each time point are presented in Table 4.5. A one-way ANOVA revealed no significant differences between trajectory groups in the proportion of expressive deficit versus withdrawal symptoms at baseline ($F = 2.22$, $p = 0.085$), suggesting that the distinct trajectories observed are not explained by differing baseline negative symptom profiles.

Table 4.5. Mean average expressive deficits and withdrawal scores by negative symptom trajectory group.

	Baseline		6 Months		12 Months	
	Exp. Deficits	Withdrawal	Exp. Deficits	Withdrawal	Exp. Deficits	Withdrawal
Minimal Decreasing	1.41	2.00	1.25	1.57	1.18	1.50
Mild Stable	1.92	2.64	2.04	2.79	2.40	3.22
High Decreasing	3.15	4.10	1.91	2.82	1.42	1.92
High Stable	3.57	3.91	3.22	3.80	3.60	3.96

Note. Expressive deficits = Blunted affect (N1), Poor rapport (N3), Lack of spontaneity (N6) and Motor retardation (G7). Withdrawal symptoms = Emotional withdrawal (N2), Passive social withdrawal (N4) and Active social avoidance (G16).

4.4.6. Predictors of Negative Symptom Course

Baseline variables with significant between class differences were entered into a multinomial regression with negative symptom trajectory class as the dependent variable. The Minimal Decreasing trajectory class served as the reference category. Full results of the multinomial regression are presented in Table 4.6.

Table 4.6. Results of multinomial regression investigating predictors of negative symptom trajectory class.

	B (SE)	Odds Ratio (95% CI)	P Value
<i>Mild Stable vs. Minimal Decreasing</i>			
Female vs. Male	-0.36 (0.30)	0.70 (0.39 – 1.25)	0.23
Non-Schizophrenia Diagnosis vs. Schizophrenia Diagnosis	0.04 (0.44)	1.04 (0.44 – 2.45)	0.94
No Family History vs. Family History	0.24 (0.48)	1.27 (0.50 – 3.21)	0.62
PAS Social - Childhood	-0.03 (0.84)	0.98 (0.19 – 5.02)	0.98
PAS Social - Adolescence	0.63 (0.84)	1.87 (0.36 – 9.65)	0.46
PAS Academic - Childhood	1.70 (0.90)	5.50 (0.94 – 32.14)	0.06
PAS Academic - Adolescence	0.52 (0.76)	1.68 (0.38 – 7.48)	0.49
Calgary Depression	0.02 (0.02)	1.02 (0.98 – 1.07)	0.35
<i>High Stable vs. Minimal Decreasing</i>			
Female vs. Male	-1.04 (0.48)	0.35 (0.14 – 0.90)	0.03
Non-Schizophrenia Diagnosis vs. Schizophrenia Diagnosis	-0.86 (0.44)	0.42 (0.18 – 1.00)	0.05
No Family History vs. Family History	-1.18 (0.44)	0.31 (0.13 – 0.72)	0.01
PAS Social - Childhood	-0.12 (1.18)	0.89 (0.09 – 8.95)	0.92
PAS Social - Adolescence	2.17 (1.12)	8.79 (0.99 – 78.11)	0.05

Continuation of Table 4.6.

PAS Academic - Childhood	0.79 (1.25)	2.21 (0.19 – 25.74)	0.53
PAS Academic - Adolescence	-0.07 (1.08)	0.93 (0.11 – 7.66)	0.95
Calgary Depression	0.05 (0.03)	1.06 (0.99 – 1.12)	0.09
<i>High Decreasing vs. Minimal Decreasing</i>			
Female vs. Male	-0.06 (0.24)	0.94 (0.60 – 1.50)	0.81
Non-Schizophrenia Diagnosis vs. Schizophrenia Diagnosis	0.37 (0.40)	1.45 (0.66 – 3.19)	0.35
No Family History vs. Family History	-0.68 (0.34)	0.51 (0.30 – 0.99)	0.046
PAS Social - Childhood	-2.21 (0.76)	0.11 (0.03 – 0.49)	0.004
PAS Social - Adolescence	2.11 (0.71)	8.26 (2.07 – 33.01)	0.003
PAS Academic - Childhood	-0.26 (0.77)	0.77 (0.16 – 3.67)	0.74
PAS Academic - Adolescence	1.01 (0.62)	2.75 (0.82 – 9.29)	0.10
Calgary Depression	0.09 (0.02)	1.09 (1.05 – 1.14)	<0.001

Note. Model: $\chi^2 (24) = 92.50$, $p < 0.001$. Family History = family history of non-affective psychosis; PAS = Premorbid Adjustment Scale

Compared to individuals in the Minimal Decreasing class, those in the High Stable class were significantly more likely to be male ($B = -1.04$, $p = 0.03$) and to have a family history of non-affective psychosis ($B = -1.18$, $p = 0.01$). Whilst those in the High Stable Class were more likely to have been given an initial diagnosis of schizophrenia and to have experienced poorer adolescent social adjustment than members of the Minimal Decreasing class, these findings just failed to reach significance (both $p = 0.05$). Compared to the Minimal Decreasing class, those in the High Decreasing class were more likely have a family history of non-affective psychosis ($B = -0.68$, $p = 0.046$) and had higher levels of depression ($B = 0.09$, $p = <0.001$). Members of the High Decreasing class had better premorbid social adjustment during childhood than the Minimal Decreasing class ($B = -2.21$, $p = 0.004$) but poorer premorbid social adjustment in adolescence ($B = 2.11$, $p = 0.003$).

4.5. DISCUSSION

4.5.1. Summary of Findings

There was significant variability in the early negative symptom trajectories of members of the EDEN cohort. LGM suggested that negative symptoms tended to be mild at baseline and decrease over time in the sample as a whole. However, there was significant variance in both the intercept and slope of the estimated individual growth trajectories. This suggests that neither levels of baseline negative symptoms nor change in individuals' negative symptoms over time are homogeneous across the sample. The single-class model fit the data poorly, suggesting that patterns of change in negative symptoms during the first 12 months of treatment cannot be satisfactorily modelled by a single trajectory. A model with four negative symptom trajectory classes was selected as the optimal model of the data. The four-class model fit the data significantly better than models with one, two or three trajectories and identified latent classes with distinct and theoretically relevant patterns of negative symptom change over the 12 month study period.

The majority of the sample (63.9%) presented with consistently minimal negative symptoms throughout the study period. This suggests that most EIP service-users do not present with notable negative symptoms at any point during the first year of treatment. Only a small proportion of the sample (5.4%) followed a trajectory of persistently high levels of negative symptoms. A further 13.5% of the sample presented with consistently elevated negative symptoms of lesser severity.

Membership of the class with the highest levels of persistent negative symptoms was predicted by male gender and family history of non-affective psychosis. A trajectory of initially high but decreasing negative symptoms was followed by 17.1% of the sample. This suggests that negative symptoms observed early in the course of EIP service-use often remit within the first 12 months of treatment. Those with remitting negative symptoms were distinguished from those with consistently minimal negative symptoms by poorer premorbid social adjustment during adolescence despite better social adjustment during childhood. They were also more likely than

those with consistently minimal negative symptoms to have a family history of non-affective psychosis and had higher baseline depression scores.

4.5.2. Interpretation, Relevance to the Literature and Theoretical Significance

4.5.2.1. The Course of Negative Symptoms in FEP

Most previous negative symptoms research has emphasised just two categories of patients: those with persistent negative symptoms and those without. However, the results of the current study suggest that such an approach does not capture the complexity of patterns in negative symptom change following FEP. Whilst most previous studies have considered those with persistent negative symptoms to be a homogeneous group, the current study identified two distinct elevated negative symptom trajectories. The mean intercept of both these trajectories was sufficiently high to indicate multiple clinically significant negative symptoms. A rating of '4' on the PANSS indicates that the symptom 'represents a serious problem' and is commonly interpreted as the threshold for clinical significance. A participant with an average negative symptom score of 3.58, the unstandardised mean intercept of the High Stable trajectory class, might have rated '4' for six out of seven negative symptom items. A participant with an average negative symptom score of 2.19, the unstandardised mean intercept of the Mild Stable group, might have rated '4' for two of the seven negative symptom items. Since a priori cut-offs typically require only one or two negative symptoms to be present, it is likely that members of both trajectory classes would be classified as having persistent negative symptoms on the basis of such criteria. Thus research employing a categorical approach based on a priori criteria for negative symptom persistence might mask considerable intra-category variation in symptom severity.

The large proportion of the sample found to have presented with consistently minimal negative symptoms throughout is surprising given that estimates of the cross-sectional prevalence of negative symptoms in FEP have been as high as 90% (Mäkinen et al., 2008). The high proportion of individuals with consistently low

levels of negative symptoms in the current study might be accounted for by characteristics of the EDEN cohort. Since the EIP services used by the study's participants follow a policy of tolerating initial diagnostic uncertainty (Department of Health, 2001), the sample is likely to be more heterogeneous than those of studies that limit participation to those with a confirmed schizophrenia-spectrum diagnosis. Further, the majority of EIP service-users are identified and treated in the community, and this may account for the high prevalence of consistently minimal negative symptoms relative to studies in which participation is limited to individuals who were inpatients at baseline (e.g. Gerbaldo, Georgi, & Pieschl, 1997; Subotnik et al., 1998).

The considerable proportion of those participants presenting with high levels of negative symptoms at baseline who experienced a remission of these symptoms within 12 months is a cause for optimism. Contrary to often pessimistic assumptions about the course of negative symptoms, a recent systematic review and meta-analysis of longitudinal studies of negative symptoms found that negative symptoms tend to decrease over time in outpatient schizophrenia samples (Savill, Banks, Khanom, & Priebe, 2015). The current study suggests the same overall trend may be evident in FEP, accounted for primarily by marked reductions in the negative symptom severity of a small subgroup. It is unclear whether such reductions in negative symptom severity should be attributed to successful treatment of secondary negative symptoms, natural recovery, or something else. This study was not designed to answer the question why do negative symptoms remit in some people but not others, however differences in the baseline characteristics of the High Decreasing and High Stable trajectory classes may provide some clues and are of particular theoretical interest.

A recently published study that used latent class analysis to investigate negative symptom trajectories over a 10 year period post-FEP (Austin et al., 2015) indicates that those who do not experience decreases in their negative symptom severity within the first 12 months of treatment may do so subsequently. A latent class comprising 19% of Austin et al.'s sample presented with an initial increase in negative symptoms during the first two years of treatment followed by a gradual

decrease to minimal levels during the remaining eight years. However, a larger latent class (26% of the sample) experienced an initial reduction in negative symptom severity followed by steadily increasing negative symptoms during the remainder of the study period. This tempers the optimism engendered by the current study, suggesting that early negative symptom remission might be followed by relapse in subsequent years. However, Austin et al.'s sample had been participants in the OPUS trial (Petersen et al., 2005) and, as such, only half had received specialist EIP treatment during the first two years. Austin et al. observed striking differences in the negative symptom trajectories followed by those who received specialist EIP treatment relative to those who did not. Thus it is plausible that the negative symptom trajectories of the EIP service-users who were the focus of the current study may differ from those of other FEP patients.

Two subdomains of negative symptoms – diminished expression and withdrawal (avolition/asociality) – have now been established (see section 1.4.3). Therefore, a question arose whether the negative symptom trajectory classes identified differed in the relative prominence of these two negative symptom subdomains. It seemed plausible that those whose negative symptoms remitted might have been those who presented with a higher proportion of symptoms from one or the other subdomains compared to those whose symptoms remained elevated. However, we found no significant differences between trajectory groups in the proportion of expressive deficit versus withdrawal symptoms at baseline. This suggests that the differing negative symptom trajectories observed were not accounted for by differences in baseline negative symptom type. Nonetheless, it is certainly true that the findings of the current study would have been different had trajectories of diminished expression and withdrawal symptoms been modelled separately. A recent study of negative symptom course during the first five years of treatment for FEP found diminished expression symptoms to be both less prevalent and less persistent than symptoms from the avolition/asociality domain (Norman et al., 2015).

4.5.2.2. Predictors of Negative Symptom Course

In line with previous research indicating an association between male gender and negative symptom severity, male gender was found to predict a trajectory of stably high negative symptoms. Whilst it is tempting to look to a biological explanation for this difference, and there may well be a role for biology in explaining differing symptom profiles, there are also plausible psychosocial explanations of such differences. For instance, Read & Beavan (2013) argue that the higher incidence of prominent negative symptoms in men might reflect the adoption of an extreme masculine role involving restriction of emotional expression. According to cognitive models, negative symptoms can be viewed as active attempts to cope with stress through withdrawing and restricting expression. Since avoidant coping strategies are more often adopted by men than by women in the general population (Eschenbeck, Kohlmann, & Lohaus, 2007; Matud, 2004), it may be that the relationship between male gender and less favourable negative symptom course following FEP is symptomatic of more men than women employing strategies of avoidance to cope with the stress associated with psychosis.

Poor premorbid social adjustment during adolescence was identified as a predictor of initially high but decreasing negative symptoms and approached significance as a predictor of stably high negative symptoms. It has been argued that poor premorbid adjustment may reflect early symptomology during the prodromal phase of the disorder (Häfner, Nowotny, Löffler, an der Heiden, & Maurer, 1995). The prodromal phase of psychosis is more often characterised by negative symptoms than by attenuated psychotic symptoms (Häfner et al., 1999). As such, it may be that the poor premorbid social adjustment of those with high levels of negative symptoms at baseline may reflect negative symptoms having been present during the prodromal phase of psychosis. That those with initially high but remitting negative symptoms were functioning significantly better during childhood than those who presented with consistently minimal negative symptoms aligns with this hypothesis.

An alternative theory in line with cognitive models of negative symptoms is that social failure in adolescence engenders negative beliefs about the self, and primes expectations of failure and lack of pleasure in demanding situations. These expectations create a predisposition to adopt a strategy of withdrawal and avoidance when faced with stressful situations, which manifests as negative symptoms in the context of psychosis. This theory places poor premorbid adjustment as a precursor of negative symptoms rather than their consequence. Of course, it may be that a circular relationship exists whereby poor premorbid functioning creates a dysfunctional cognitive set, which leads to the emergence of prodromal negative symptoms, which serves to reinforce the dysfunctional beliefs, which worsens the prodromal negative symptoms. Prospective studies examining the relationship between poor premorbid functioning, dysfunctional beliefs and negative symptoms will be required to disentangle the relationship between these factors during early psychosis.

Previous research has suggested that premorbid social adjustment is of most relevance for negative symptoms, whilst premorbid academic adjustment is linked to cognitive outcome (Chang et al., 2013). The current study supported this suggestion; social but not academic adjustment during adolescence distinguished the High Decreasing class from the Minimal Decreasing class and the same trend in the same direction was observed between the High Stable class and Minimal Decreasing class. This might be because negative symptoms reflect primarily social deficits; blunted affect, alogia and asociality all reflect a reluctance or inability to engage with others. Therefore, if it is assumed that poor premorbid functioning results from the emergence of negative symptomology during the prodrome, it makes sense that social functioning would be impacted to a greater extent than academic functioning. Likewise, adverse social experiences might be more likely than academic failure to prime the avoidant coping strategies that have been proposed to underlie negative symptoms.

Family history of non-affective psychosis was a further factor whose hypothesised relationship with negative symptom trajectories was supported by the current study. Having a family history of non-affective psychosis predicted membership of both the High Stable class and High decreasing class. This might suggest a genetic

predisposition to elevated negative symptoms. It has been proposed that enduring negative symptoms might be the result of neurodevelopmental impairment resulting from genetic defects (Carpenter, Buchanan, Kirkpatrick, Tamminga, & Wood, 1993; Murray, 1994). However, this would not explain the relationship between family history and negative symptoms that swiftly remitted. Another possible explanation is that young people with a parent or sibling with non-affective psychosis might be more likely to experience adverse life-events (e.g. bullying, poverty, being a young carer) and that this might contribute to the development of negative symptoms. A third possible explanation of the relationship between negative symptom course and family history is that a care giver with non-affective psychosis may be less able to model adaptive coping strategies. An individual who has not learnt how to cope with stress effectively might be more likely to manifest negative symptoms.

The association between higher baseline depression scores and membership of the trajectory class with initially high but remitting negative symptoms might suggest that members of this class were presenting with negative symptoms secondary to depression. The remission of this group's negative symptoms might then be attributed to successful treatment of their depression. However, since only baseline depression was considered in the current study, it is not known whether the High Decreasing class did indeed experienced reductions in depression that might account for the remission of their negative symptoms. Further research is required to establish what role depression might play in the course of negative symptoms following FEP.

That DUP was not associated with negative symptom class in the current study was surprising given that a meta-analysis of 16 studies involving 3339 FEP participants concluded that DUP of less than nine months is associated with less severe negative symptoms at both short and long-term follow up (Boonstra et al., 2012). It is possible that this discrepancy is a result of differing methods; the studies Boonstra et al. synthesised examined group level correlations between DUP and negative symptom severity as opposed to the association between DUP and specific negative symptom trajectories. Austin et al. (2015), who employed similar methods to the current study, did not find DUP to be a significant predictor of negative symptom course, though

they did find an association between longer DUP and negative symptom course in their univariate analyses.

Also contrary to expectations, no association between illicit substance use and less persistent negative symptoms was observed in the current study. However, there were significant limitations in the measurement of substance use in this study which may have impacted the results. Participants who reported lifetime use of any illicit substance were treated as a single group for the purposes of the analysis. It is possible that there may be a different relationship between negative symptom course and infrequent use of recreational drugs, and negative symptom course and habitual substance abuse that were obscured by the methods employed in this study.

4.5.3. Limitations

As previously discussed, missing data were estimated using FIML under the assumption that data were missing at random (MAR). However, unfortunately there was evidence of an association between missingness and negative symptom severity – those with less severe negative symptoms at baseline were more likely to be lost to follow up than those with more severe negative symptoms – which suggests that the MAR assumption is not justified. Arguably, in a study of negative symptoms, it is preferable that participants with less severe negative symptoms be lost to follow-up rather than those with more severe symptoms. Nonetheless, the results of a study will inevitably be biased by the loss of participants with a particular negative symptom profile, however this is dealt with.

As a check on the impact of the decision to use all available data as opposed to excluding those participants deemed to have insufficient PANSS data, the LCGA was repeated including only participants with complete PANSS data at baseline and at least one subsequent time point ($n = 848$). The analysis yielded classes that followed trajectories with intercepts and slopes extremely similar to those of the original model (see Appendix A). Only four individuals (less than 0.5% of the sample subset) were allocated to a different class in this repeat analysis to that they

were allocated to in the original model. This suggests that the estimation of missing data points using FIML, rather than excluding participants deemed to have insufficient data for the estimation of a trajectory, had minimal impact on the conclusions reached.

Since participants were assessed at only three time points, the model forms that could be fitted to the data were limited. Further, the follow-up period of the current study was relatively short. Whilst the first 12 months of treatment are an important period for research given EIP services' focus on providing intensive support soon after psychosis onset, it is possible that further trajectories would emerge if participants were followed over a longer period. For instance, Evensen et al. (2012), in their study of the course of blunted affect over a 10 year period, found that 16% of participants developed blunted affect over the course of the follow-up period. Thus, it is possible that a trajectory of increasing negative symptoms would have emerged had negative symptoms been assessed over a longer time period. A longer term follow-up incorporating more frequent assessment would provide a more nuanced picture of variation in negative symptom course.

The retrospective nature of several baseline measurements might have impacted the findings. Participants were required to recall their premorbid functioning, pathway to care, family history of mental illness, and previous substance use after the onset of psychosis and commencement of treatment with EIP. Since current symptomatology and treatment might conceivably have an impact on participant recollection or reporting, there is a risk of recall bias having influenced the findings. This limitation could only be fully overcome by recruiting participants prior to the onset of their psychosis and following them prospectively, for instance as part of a birth cohort study.

Since the current study made use of data collected as part of the EDEN programme, the potential predictors of negative symptom course available for exploration were limited to those variables present in the dataset. Factors that may have been relevant to understanding variability in early negative symptom course were not included in

the analysis for this reason. For instance, the neurocognitive functioning of members of the EDEN cohort was not measured and thus neurocognitive variables were not included as potential predictors in the current analysis. However, neurocognitive deficits, including verbal memory impairments, have been found to be associated with persistent negative symptoms in FEP (Hovington, Bodnar, Joober, Malla, & Lepage, 2013). The relationship between neurocognitive functioning and other negative symptom trajectories is worthy of further investigation.

4.6. CONCLUSION

Negative symptom course following FEP is characterised by distinct trajectories. Persistent negative symptoms are observed in only a small proportion of those experiencing FEP and are associated with male gender and a family history of non-affective psychosis. Decreasing negative symptoms are observed in a sizeable subgroup of those with elevated negative symptoms on entry to EIP. Membership of the trajectory class characterised by initially elevated but decreasing negative symptoms is predicted by relatively good social adjustment during childhood but relatively poor social adjustment during early adolescence, high depression at baseline, and a family history of non-affective psychosis.

Chapter Five – The Relationship Between Negative Symptom Course and Social Recovery in First-Episode Psychosis

5.1. BACKGROUND AND RATIONALE

5.1.1. Social Disability and Psychosis

Many individuals who experience psychosis have difficulties in a range of social domains including work, study, social relationships and independent living. Such social disability is already evident by the time individuals present with their first psychotic episode: compared to matched controls, individuals with FEP are less likely to be employed, less likely to be in a romantic relationship, and have fewer friends (Macdonald, Hayes, & Baglioni, 2000; Morgan et al., 2008). Indeed, difficulties with social functioning often predate the emergence of positive psychotic symptoms (Häfner et al., 1995), and thus functional decline is acknowledged to be an important indicator of psychosis risk (Yung et al., 2005). Moreover, there is evidence that early social disability is sustained in the longer-term. A study of the 10 year outcomes of individuals recruited during their first psychotic episode identified persistently high levels of social disability (Morgan et al., 2014). Only 12% of the sample had been employed for more than 75% of the follow-up period and 72% had been employed for less than 25% of the follow-up period. Furthermore, 71% of the sample were not in a romantic relationship during most of the follow-up period.

Morgan et al. contrasted the poor social outcomes of participants with their relatively good symptomatic outcomes; only a minority of participants experienced continuous psychotic symptoms during the follow-up period and almost half had been completely free of positive psychotic symptoms for the two years prior to follow up. It has long been known that functional recovery is largely independent of recovery from positive symptoms (Carpenter & Strauss, 1977). Social disability has been found to persist in the absence of ongoing positive symptoms (Henry et al., 2010). Equally, some individuals make a good social recovery despite ongoing psychotic symptoms (Amminger et al., 2011; The British Psychological Society, 2014).

5.1.2. The Relationship between Negative Symptoms and Functional Outcome

Whilst social functioning and positive psychotic symptoms are largely independent of one another, this is not true of social functioning and negative symptoms. The association between negative symptom severity and poor functional outcomes is well established (Álvarez-Jiménez et al., 2012). Studies have found negative symptoms to be of greater prognostic importance for later functioning than not only positive symptoms (Ho, Nopoulos, Flaum, Arndt, & Andreasen, 1998; Hoffmann, Kupper, Zbinden, & Hirsbrunner, 2003; Lysaker & Davis, 2004; Rabinowitz et al., 2012), but also cognitive impairment (Guaiana, Tyson, Roberts, & Mortimer, 2007; Leifker, Bowie, & Harvey, 2009). Negative symptoms that persist despite antipsychotic treatment are of particular prognostic importance; such negative symptoms predict poorer functional outcome than negative symptoms that prove more transient (Chang et al., 2011; Galderisi et al., 2013; Husted, Beiser, & Iaconoc, 1992). The poor social functioning of those who present with elevated negative symptoms is a key motivator of the drive to develop effective treatment strategies for negative symptoms (Elis et al., 2013; Kirkpatrick et al., 2006).

Whilst the relationship between persistent negative symptoms and poor functional outcome is well established, few studies have looked at longitudinal change in negative symptoms and improvement in functioning concurrently. Fluctuations in negative symptoms have been shown to coincide with fluctuations in functioning over time in a sample of individuals with chronic schizophrenia taking part in a supported employment programme (Erickson, Jaafari, & Lysaker, 2011). However, it is not known whether improvements in negative symptom severity are accompanied by concurrent improvements in social functioning early in the course of psychosis. The current study investigated the relationship between the trajectory of an individual's negative symptoms during the first 12 months of treatment for FEP and their social recovery trajectory during the same period.

Better understanding the relationship between the early course of negative symptoms and concurrent change in functioning might provide clues as to the nature of the relationship between negative symptom severity and poor functioning. Erickson et al. (2011) accounted for the close temporal relationship they observed between increases in negative symptom severity and deteriorations in functioning by noting the importance of communication and motivation to successful occupational functioning. That negative symptoms have a detrimental impact on the ability to function successfully, i.e. there is a direct causal relationship between negative symptoms and poor functioning, is implicit in many authors' discussions of the relationship between negative symptoms and poor functional outcome. However, there is evidence to suggest that the relationship between negative symptoms and functioning may be bi-directional with negative symptom severity predicting later functional outcome, as well as early functional outcome predicated later chronicity of negative symptoms (Álvarez-Jiménez et al., 2012). Further, it is possible that the relationship between negative symptoms and functioning is not direct, but mediated by other variables.

5.1.3. Measuring Social Recovery: The Time Use Survey

Good social and occupational functioning have been deemed to be among the most important markers of recovery, both by experts by professional experience (Kane, Leucht, Carpenter, & Docherty, 2003), and by experts by lived experience (Pitt, Kilbride, Nothard, Welford, & Morrison, 2007). However, there is no consistent way of measuring social and occupational functioning in psychosis (Mausbach, Moore, Bowie, Cardenas, & Patterson, 2008), and no consensus criteria for a good functional outcome (Menezes, Arenovich, & Zipursky, 2006).

The current study uses time spent in 'structured activity' as measured by the Time Use Survey (TUS) as a measure of social recovery, conceptualised as the process of getting one's life "back on track" after an episode of psychosis. The original version of the TUS, consisting of detailed daily diaries supplemented by a structured interview, was designed by the Office for National Statistics for use in a nationwide

study of how individuals in the UK spend their time (Short, 2003). The TUS was modified for use with psychiatric populations by Fowler and colleagues. The key modifications to the original measure included: (1) limiting the types of activities enquired about to those relevant to the assessment of time spent in constructive economic and structured leisure activities, and (2) omitting the requirement for participants to complete daily diaries, instead collecting all information required via a semi-structured interview. These modifications were intended to minimise the burden placed on participants and thus increase the likelihood of obtaining complete data. The modified version of the TUS has been successfully used both with individuals with early psychosis and those at risk of psychosis (Fowler et al., 2009b; Hodgekins et al., 2015b).

During the interview the participant is asked detailed questions about how they spent their time during the previous month. Lists of activities are provided by the interviewer and where the participant reports having engaged in a listed activity, further questions are asked to assess frequency and duration. Activities inquired about include employment, education, voluntary work, childcare, housework, leisure activities, hobbies, socialising, rest, and sleeping. Information obtained from this interview is used to provide an estimate of the average number of hours per week the participant has spent engaging in structured activity over the previous month. Structured activity is defined as time spent engaging in work (paid and voluntary), education, childcare, housework, sport and structured leisure activities (e.g. going to the cinema, on a shopping trip, eating out, attending a sporting or cultural event, or participating in a community group).

The main strength of the use of the TUS in the context of this study is that it provides a measure of functional outcome with limited conceptual overlap with negative symptoms, reducing the risk of confounding. Many of the measures used to quantify functional outcome, including those that have been employed in studies investigating the association between negative symptoms and functioning, contain content that overlaps significantly with that of negative symptom measures. For instance, a frequently employed measure of functional impairment is the Quality of Life Scale (QLS; Heinrichs, Hanlon, & Carpenter, 1984). The QLS is a 21-item

interviewer-rated instrument designed to measure deficit symptoms (i.e. enduring negative symptoms) during the preceding four weeks. Items included in the QLS include social initiative and withdrawal, degree of motivation, emotional interaction, and anhedonia, all of which clearly intersect with the negative symptoms construct. Other commonly used measures of social functioning in psychosis contain items which similarly overlap with negative symptoms. For instance, the Social Functioning Scale (Birchwood, Smith, Cochrane, Wetton, & Copestake, 1990) contains items which assess the quality of a participant's communication and ability to initiate conversations, both likely to overlap with ratings of alogia, and an item measuring social avoidance, almost certainly a confound with asociality.

A more general strength of the TUS as a measure of social functioning is its relative objectivity. The interviewer is not required to make any judgements about a participant's quality of life, degree of social competence, or independent living skills; instead the score derived is a direct reflection of the amount of time the participant reports having spent engaged in the activities of interest. As such, very high levels of inter-rater reliability have been observed (Hodgekins et al., 2015b). A further strength of the measure is its emphasis on activities beyond paid employment. Definitions of social recovery have often emphasised competitive employment to the exclusion of other economically valuable and personally meaningful activities. For instance, Warner (2004) defines social recovery as: "economic and residential independence and low social disruption. This means working adequately to provide for oneself and not being dependent on others for basic needs or housing" (p.56).

In line with this definition, many studies have used paid employment as a marker of social recovery, yet this approach is problematic for a number of reasons. First, it devalues non-paid work including voluntary work, housework and childcare. The economic value of unpaid work is increasingly being recognised: the annual economic contribution of volunteers to the UK economy has recently been estimated at £41.5 billion (Volunteering England, 2009). Moreover, unpaid work can provide a meaningful and valued life role (Pitt et al., 2007). Second, economic independence is arguably a developmentally inappropriate expectation for many individuals with FEP

in their teens or early twenties, whose peers will often still be engaged in education or training. Further, employment status is unlikely to provide a sufficiently sensitive measure to capture the subtle changes in social functioning which may be significant indicators of recovery following FEP. The TUS overcomes these limitations by measuring a range of economically and personally beneficial activities in addition to time spent in paid employment.

The current study builds upon a prior analysis of the National EDEN dataset conducted by Hodgekins et al. (2015a). Hodgekins et al. investigated longitudinal change in social functioning following FEP by using LCGA to model hours spent in structured activity (as measured by the TUS). Three social recovery trajectories were identified: (1) low levels of social functioning sustained over the course of the study ('Low Stable'), (2) moderate social functioning which improved slightly over the course of the study ('Moderate Increasing'), and (3) initially high social functioning which decreased slightly over the course of the study but remained high ('High Decreasing'). The trajectories are represented graphically in Figure 5.1.

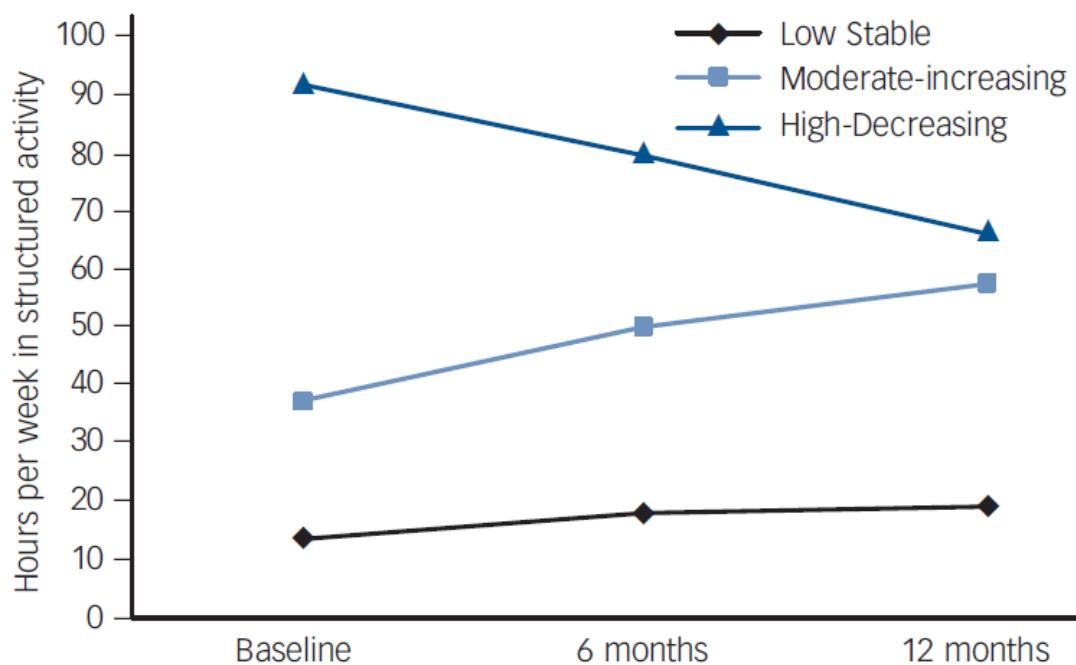


Figure 5.1. LCGA model with three social recovery trajectories reproduced from Hodgekins et al. (2015a).

The Low Stable trajectory class comprised the majority (66%) of the cohort. The Moderate Increasing class had the second largest membership, accounting for 27% of the sample. The High Decreasing trajectory was the least common: only 7% of the sample were members of this class. The availability of data on time use from both a general population sample and from individuals with psychosis has enabled empirically grounded clinical cut-offs to be calculated (Hodgekins et al., 2015b). UK residents aged 16-35 years spend an average of 63.5 hours per week engaged in structured activity (Short, 2006). Participants engaging in less than 45 hours per week of structured activity can be defined as at risk of social disability, those engaged in less than 30 hours per week can be defined as experiencing social disability, and those engaging in less than 15 hours per week can be defined as experiencing severe social disability.

As both the Moderate Increasing and High Decreasing trajectories were engaged in amounts of activity within the non-clinical range by the end of the study period, members of both these classes might be deemed to have made a ‘good social recovery’. In the case of the High Decreasing group, whose hours per week in structured activity decreased during the follow-up period, it might seem rather counterintuitive to talk of them having made a ‘good social recovery’. However, since this group were engaging in very high levels of structured activity at baseline – over 90 hours per week on average – the decrease in their activity to levels more in line with those of their peers might equally be seen as indicative of recovery. Since the Stable Low trajectory class were consistently engaged in levels of structured activity indicative of social disability, this class might be deemed to have made a ‘poor social recovery’.

The current study aims to increase understanding of the relationship between negative symptom severity and functioning during FEP through investigating the social recovery trajectories followed by members of the negative symptoms trajectory classes described in the previous chapter. The proportion of individuals from each of the negative symptom trajectory classes who make a ‘good’ social recovery versus those who make a ‘poor’ social recovery will also be examined.

5.2. RESEARCH QUESTION

What is the relationship between the trajectory of an individual's negative symptoms during the first 12 months of treatment for FEP and their social recovery trajectory over the same period?

5.3. METHODS

5.3.1. Design

This study has a longitudinal design with participants having been assessed at three time points: baseline, six and twelve months. Negative symptoms were assessed at all three time points using the PANSS. Social functioning was assessed at all three time points using the TUS.

5.3.2. Participants

Only those participants who completed the TUS at at least two time points ($n = 764$) were included in the analysis of social recovery trajectories. The total number of participants included in the analysis of the association between negative symptom trajectories and social recovery trajectories is 759 individuals (those National EDEN participants eligible for inclusion in the current study who were also included in the analysis of social recovery trajectories).

5.3.3. Sample Size

A power calculation carried out using G*Power Version 3.1.9.2 (Faul et al., 2007) found that to achieve 90% power with a significance level of 0.05, an estimated medium effect size and six degrees of freedom a minimum sample size of 194 would be required. Thus the study was adequately powered.

4.3.4. Procedure

The procedures were as described in the Chapter Three (section 3.3.4). The National EDEN measures included in the current study are described in the following section.

5.3.5. Measures

5.3.5.1. Positive and Negative Syndrome Scale (Kay, Fiszbein, & Opler, 1987)

As previously described (section 4.3.5.1), the mean score of seven PANSS items – ‘blunted affect’ (N1), ‘emotional withdrawal’ (N2), ‘poor rapport’ (N3), ‘passive social withdrawal’ (N4), and ‘lack of spontaneity and flow of conversation’ (N6), ‘motor retardation’ (G7) and ‘active social avoidance’ (G16) – was used as the measure of negative symptoms. A detailed explanation of the rationale for the use of these seven PANSS items, as opposed to the negative subscale of the PANSS, to measure negative symptom severity is provided in Chapter Three.

5.3.5.2. Time Use Survey (Short, 2003)

Social functioning was measured using the TUS. As previously outlined, the TUS is a semi-structured interview designed to provide an objective assessment of the amount of time the participant has spent engaged in structured activity over the previous month. Information obtained from this interview is used to estimate of the total time spent in structured activity each week on average over the previous month. For further information about the TUS and the rationale for its use as a measure of social functioning see section 5.1.3 above.

5.3.6. Analysis Plan

Statistical analyses were carried out using SPSS for Windows, Version 22 (IBM, 2013).

The social recovery trajectory class of the members of each of the negative symptom trajectory classes outlined in the previous chapter were identified by matching the participants included in Hodgekins et al.'s LCGA with those included in the negative symptoms LCGA described in the previous chapter using participants' identifier codes. A matrix of all the possible combinations of negative symptom and social recovery trajectories was constructed and individuals assigned to cells of the matrix according to their trajectory permutation. The independence of negative symptom and social recovery trajectory class membership was then tested statistically using Pearson's Chi-Squared test. Examination of the adjusted standardised residuals of this Chi-squared test was used to determine which combinations of the two trajectory classes were over/under-represented in the sample relative to what would be expected were the two sets of latent classes independent of one another.

The proportion of each negative symptom trajectory class that made a 'good social recovery' during the study period – defined as membership of the Moderate Increasing or High Decreasing trajectory class – was calculated and represented graphically.

5.4. RESULTS

As previously outlined, Hodgekins et al. (2015a) identified three trajectories of social functioning: (1) low levels of social functioning sustained over the course of the study (Low Stable); (2) moderate social functioning which improved slightly over the course of the study (Moderate Increasing); and (3) initially high social functioning which decreased slightly over the course of the study but remained high (High Decreasing). In order to explore the relationship between these three social functioning trajectories and the four negative symptom trajectories identified, a

matrix of negative symptom trajectory class against social recovery trajectory class was constructed (Table 5.1).

Table 5.1. Matrix of intersections between negative symptom trajectory classes and social functioning trajectory classes.

		Social Recovery Trajectory Class		
		<i>High Decreasing</i>	<i>Moderate Increasing</i>	<i>Low Stable</i>
Negative Symptom Trajectory Class	<i>Minimal Decreasing</i>	n = 44 (9.0%) Significantly over-represented	n = 166 (34.1%) Significantly over-represented	n = 277 (56.9%) Significantly under-represented
	<i>Mild Stable</i>	n = 4 (4.2%) Within expected range	n = 12 (12.5%) Significantly under-represented	n = 80 (83.3%) Significantly over-represented
	<i>High Decreasing</i>	n = 4 (3.1%) Within expected range	n = 23 (17.6%) Significantly under-represented	n = 104 (79.4%) Significantly over-represented
	<i>High Stable</i>	n = 1 (2.2%) Within expected range	n = 2 (4.4%) Significantly under-represented	n = 42 (93.3%) Significantly over-represented

Note. The text in each cell refers to whether the class is over- or under-represented according to the adjusted standardised residual of the relevant Chi-Squared test.

Negative symptom trajectories and social recovery trajectories were not independent of one another ($\chi^2 = 57.06$, $p = <0.001$). Examination of the adjusted standardised residuals (ASR) of the Chi-squared test was used to determine which cells were over- and under-represented in the matrix. Trajectory permutations that were over-represented in the sample were: Minimal Decreasing negative symptoms and High Decreasing social functioning (ASR = 3.0); Minimal Decreasing negative symptoms and Moderate Increasing social functioning (ASR = 6.1); Mild Stable negative symptoms and Low Stable social functioning (ASR = 3.8); High Decreasing negative symptoms and Low Stable social functioning (ASR = 3.5); and High Stable negative symptoms and Low Stable social functioning (ASR = 4.0). Trajectory combinations under-represented in the sample were: Minimal Decreasing negative

symptoms and Low Stable social functioning (ASR = -7.3); Mild Stable negative symptoms and Moderate Increasing social functioning (ASR = -3.4); High Decreasing negative symptoms and Moderate Increasing social functioning (ASR = -2.6); and High Stable negative symptoms and Moderate Increasing social functioning (ASR = -3.5).

Since both the Moderate Increasing and High Decreasing trajectories were characterised by non-clinical levels of structured activity at 12 months, membership of either class was taken to indicate a participant having made a ‘good social recovery’. Using this definition, 43.1% of Minimal Decreasing negative symptom participants made a good social recovery versus 6.6% of High Stable negative symptoms participants. The proportion of each negative symptoms trajectory class that made a good social recovery within the study period relative to those that did not is presented graphically in Figure 5.2.

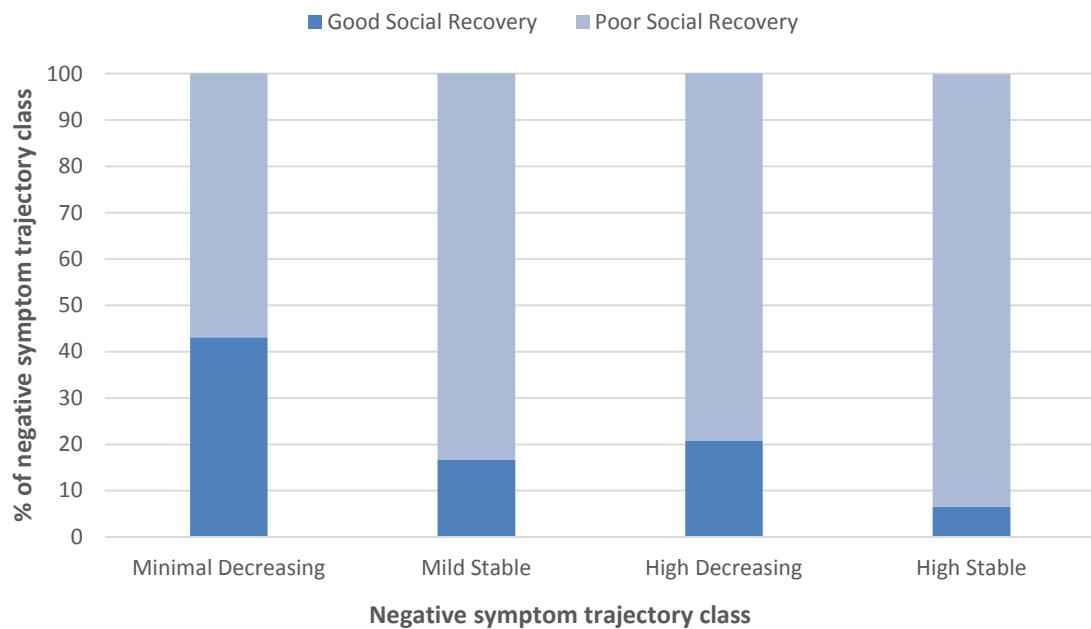


Figure 5.2. Proportion of each negative symptoms trajectory class that followed a social functioning trajectory characterised by non-clinical levels of structured activity by 12 months (‘Good Social Recovery’) versus those with stably low levels of structured activity (‘Poor Social Recovery’).

As Figure 5.2 makes evident, members of the Mild Stable, High Decreasing and High Stable were less likely to have made a good social recovery after 12 months of EIP treatment than were members of the Minimal Decreasing class. However, the figure also shows that the majority of those in all negative symptom trajectory classes, including members of the Minimal Decreasing class, did not make a good social recovery within the study period. Indeed, Minimal Decreasing/Low Stable was the most common negative symptom trajectory/social recovery trajectory permutation, accounting for 36.5% of the sample, indicating that elevated negative symptoms at baseline are not a prerequisite for poor social recovery.

5.5. DISCUSSION

5.5.1. Summary of Findings

Examination of the social recovery trajectories followed by members of each negative symptom trajectory class revealed an association between the two trajectories. Those who followed a negative symptom trajectory characterised by elevated symptoms at baseline, whether or not those negative symptoms decreased over time, were significantly less likely to make a good social recovery during their first 12 months of EIP service receipt. Those who presented with consistently minimal negative symptoms were significantly more likely to make a good social recovery than would be expected were social recovery independent of negative symptom trajectory. Nonetheless, a significant proportion of the sample failed to make a good social recovery during their first 12 months of EIP despite minimal negative symptoms throughout this period, indicating that a pattern of elevated negative symptoms does not fully account for poor social recovery.

5.5.2. Interpretation, Relevance to the Literature and Theoretical Significance

The results of the current study suggest that those who have elevated negative symptoms at baseline, even those whose negative symptoms remit early in the course of their psychosis, are less likely to achieve a good social recovery within 12 months

of treatment onset than those with consistently low levels of negative symptoms. This finding was partially unexpected: while it was predicted that persistent negative symptoms would be associated with stably low social functioning, it was anticipated that individuals who experienced a reduction in their negative symptoms would be likely to experience a corresponding increase in functioning. This prediction was based on the assumption that there is a direct relationship between negative symptom severity and functioning; that this was not borne out suggests that their relationship may be less straightforward than often assumed.

Given that those with initially high but decreasing negative symptoms were functioning relatively poorly prior to the emergence of their psychosis, the worse than anticipated social recovery of this class could be hypothesised to be a legacy of premorbid social disability. An individual who has failed to achieve key functional milestones prior to the onset of psychosis is likely to find it much more challenging to achieve a good level of functioning after its onset. Given that negative symptoms emerge before positive symptoms (Häfner et al., 1999, 1995), it is possible that the premorbid social disability experienced by the High Decreasing class was the result of prodromal negative symptoms. This would provide an explanation for the relatively poor social functioning of the High Decreasing group during adolescence despite having been relatively well adjusted during adolescence. However, it is also possible that early social disability might have a role in the initial development of negative symptoms.

There is evidence that early social disability may play a role in maintaining negative symptoms once they have emerged: Alvarez-Jiminez et al. (2012) found that failure to make a functional recovery early in the course of psychosis was a significant predictor of greater negative symptom severity six years later, independent of earlier persistence of negative symptoms. However, research also suggests that negative symptoms have a role in maintaining social disability: Brill et al. (2009) used path analysis to show that negative symptoms mediate the relationship between premorbid functioning and later functional outcomes. Taken together, these findings suggest that negative symptoms and social disability may maintain one another in a

vicious cycle, with poor social functioning leading to negative symptoms, which further entrench social disability.

That social functioning does not tend to improve as negative symptoms decrease would suggest that there is no corresponding ‘virtuous cycle’. It might be that the experience of negative symptoms early in the course of psychosis creates enduring barriers to successful functioning. Psychosis typically emerges during adolescence or early adulthood, an important development period characterised by important social and occupational transitions, such as taking examinations, finding work or moving into higher education, establishing romantic relationships, and moving to living independently. Failure to reach such milestones during adolescence as a result of negative symptoms might have far reaching effects on a person’s social recovery. For instance, poor examination results might have implications for future career prospects. This possibility suggests that intervening at the earliest stage of disorder – at the first signs of non-specific negative symptoms and social disability, rather than waiting for attenuated positive symptoms to emerge – may be necessary in order to prevent long term disability (Fowler et al., 2010).

More optimistically, it is plausible that decreased negative symptom severity does tend to be followed by improvements in functioning but that these improvements take some time to become evident. Processes such as securing employment, finding a voluntary opportunity, enrolling on a course and rebuilding a social network take time. As such, it may be that an individual whose social functioning has been disrupted by negative symptoms will experience a delay in returning to optimal levels of structured activity following the remission of these symptoms. Longer term follow-up studies will be necessary to establish the stability of social disability after early negative symptoms have remitted.

As anticipated, those who presented with consistently minimal negative symptoms were significantly more likely to make a good social recovery. However, it is also clear that a large number of FEP patients do not make a good social recovery within 12 months even in the absence of significant negative symptoms. This is a clear

indication that negative symptom severity is far from the only factor at play in poor social recovery following FEP. Poor social recovery is likely to be the result of a wide range of interacting factors, including symptoms and neurocognition but also social and economic factors (Warner, 2004). As such, improved rates of social recovery following FEP will not be achieved by focusing on any one factor in isolation.

5.5.3. Limitations

The amount and pattern of missing social recovery data is an important limitation of the study. Of the 1006 participants included in the previous study, 247 were not included in the current study as their social recovery trajectory was not modelled due to insufficient TUS data. The participants for whom social recovery trajectories were not available did not differ from participants for whom it was available in terms of age of psychosis onset, baseline diagnosis, DUP, gender, ethnicity, or employment status (Hodgekins et al., 2015a). However, there was an association between the negative symptom trajectory class of participants and whether or not sufficient TUS data was available for a social recovery trajectory class to be modelled. Those with more severe and persistent negative symptoms were more likely to have sufficient data: 90% of High Stable class members had a social recovery trajectory class versus only 72.3% of the Minimal Decreasing class.

The impact of the relative lack of social functioning data for those with less severe negative symptoms is not possible to access with precision. However, even if all those Minimal Decreasing negative symptom class participants for whom social functioning trajectory data was missing had been in the Stably Low social functioning class, there would still have been an association between negative symptom trajectory and social recovery trajectory ($\chi^2 = 24.07$, $p = 0.001$), with the Minimal Decreasing negative symptoms and Stably Low social functioning permutation still significantly under-represented (ASR = -4.5). As such, the pattern of missing social recovery trajectories is unlikely to have impacted the conclusions reached.

The methods used in this study were only able to paint a broad-brush picture of the relationship between negative symptom course and concurrent social recovery. Further insights into their relationship could have been generated through the use of alternative methods. For example, if sufficient data had been available the social functioning trajectories of each negative symptom trajectory class could have been modelled individually. This may have revealed greater nuances in the relationship between negative symptoms and social functioning. However, introducing greater complexity to the analysis may also have decreased the interpretability of the data; since each round of modelling would have yielded a unique set of trajectories it would not have been possible to directly compare the occurrence of trajectories across groups, limiting the conclusions that could be drawn.

While the amount of time spent in structured activity is a useful marker of recovery, there are clear limitations of prescribing whether or not an individual has made a ‘good’ social recovery on the basis of this alone. First, it does not necessarily capture everything that is important to an individual’s social recovery, for instance it does not measure the quality of engagement in activities, whether individuals are able to connect with those around them, or feel that they have a valued role in society. Second, multiple domains of functioning, including vocational, residential and interpersonal functioning, are conflated within the category of structured activity. However, there is evidence that some domains of functioning might be more closely associated with negative symptom severity than others, for instance, one study found that there may be a closer relationship between negative symptoms and interpersonal functioning than residential functioning (Leifker et al., 2009).

What is more, the TUS does not take into account the personal meaning attributed to the activities it enquires about, leading to a rather prescriptive definition of what constitutes a ‘good’ recovery. The relationship between negative symptom course and subjective conceptions of recovery should be considered alongside normative definitions of recovery. The personal understandings of recovery of those with differing negative symptom trajectories are explored in Chapter Seven of this thesis.

5.6. CONCLUSION

Those with elevated negative symptoms at baseline are disproportionately likely to experience a lack of improvement in their social functioning over the first 12 months of their engagement with EIP services. Unexpectedly, this is the case even when those negative symptoms remit within 12 months. Further research is needed to ascertain whether social disability is sustained in this group or if improvements in social functioning are merely delayed relative to reductions in negative symptoms. Those with consistently low levels of negative symptoms are more likely to make a good social recovery than other FEP patients. Nonetheless, given that the majority of such patients will not have reached a level of social functioning comparable to their peers within 12 months, the social recovery needs of this group should not be overlooked.

INTERLUDE

From Quantitative to Qualitative Investigation: The Merits of Mixing Methods

The strength of qualitative research is its ability to provide complex textual descriptions of how people experience a given research issue. It provides information about the “human” side of an issue – that is, the often contradictory behaviours, beliefs, opinions, emotions, and relationships of individuals ... When used along with quantitative methods, qualitative research can help us to interpret and better understand the complex reality of a given situation and the implications of quantitative data.

(Mack, Woodsong, MacQueen, Guest, & Namey, 2005, pp. 1–2)

The studies described in Part Two used quantitative methods to investigate the factor structure of the PANSS in FEP, the course of negative symptoms during FEP, and the relationship between negative symptom course and social recovery. The findings demonstrate that there is a high degree of heterogeneity in negative symptom course following FEP but that it is possible to distinguish latent classes with similar negative symptom trajectories within this heterogeneous group. Further, the results suggest that the trajectory of an individual’s negative symptoms can, at least in part, be accounted for by demographic and baseline clinical characteristics. Following a trajectory characterised by elevated negative symptoms on entry to EIP services appears to have worrying implications for the likelihood of making a good social recovery within 12 months.

Quantitative methods are extremely valuable in that they are capable of generating findings that can be generalised to a wider population. However, reducing the complex behaviours, beliefs, emotions and relationships of human beings to a set of numbers inevitably leaves much uncaptured. Whilst statistical findings are informative at the level of the population of EIP service-users, they tell us little about the experiences of the individuals who make up this population. Further, they provide only limited information about the underlying processes that generate the statistical regularities observed. The use of qualitative methods alongside quantitative methods in the research conducted for this thesis was intended to minimise these limitations.

Whereas the quantitative research carried out aimed to produce findings generalisable to the population of EIP service-users, the qualitative research aimed to provide rich insights into the experiences of individual members of this population. To meet this aim, transcripts of in-depth interviews with a subsample of participants from each of the identified trajectory classes were analysed thematically in order to learn about the individual experiences of members of each class. Exploring the experiences of individual participants was considered important because of the potential for such exploration to provide insights into the complex psychosocial processes underlying differing negative symptom trajectories. These insights might aid in the interpretation of the quantitative findings, exposing the mechanisms underlying persistent negative symptoms following FEP and offering possible explanations of the relationship between elevated negative symptoms on entry to EIP and delayed social recovery.

Further, exploring the experiences of individual service-users presents the opportunity to gain a more complete understanding of the phenomena at hand. Psychiatric symptoms, including negative symptoms, are conceptualised as experiential as well as behavioural phenomena. As such, neglecting to consider what it is *like* to be a person presenting with negative symptoms is to leave a fundamental aspect of negative symptoms unexamined. It is only by seeking to take the perspective of individuals with lived-experience that this experiential dimension of negative symptoms is revealed.

Greene et al. (1989) identified five distinct rationales for the integration of quantitative and qualitative methods. The use of mixed methods in the current research spans three of these rationales: complementarity, development and expansion. Complementarity denotes the potential for findings obtained using one method to elaborate, illustrate or clarify the findings of another. In the current research, the qualitative work was designed to illustrate and aid interpretation of the quantitative findings through the focus on individual lived-experiences. Development refers to using one method to extend work conducted using the other. Most commonly the quantitative aspect of a study builds upon earlier exploratory work using qualitative methods. Conversely, in the current research, the qualitative

work was a development of the quantitative research; the findings of the quantitative work informed sampling decisions and guided the choice of research questions in the qualitative phase.

Expansion describes the potential for mixed methods research to address a wider breadth of questions than could be answered using a single method. Research questions regarding the lived-experiences of individual service-users could not have been satisfactorily addressed through the use of quantitative methods alone, likewise questions about the course of negative symptoms and relationship with social recovery in the population of EIP service-users could not have been effectively answered through the use of qualitative methods alone. Therefore, the scope of the thesis was expanded through the adoption of a mixed methods approach.

Part Three of the thesis reports the qualitative phase of the research before the quantitative and qualitative findings are brought together in Part Four.

PART THREE

A Qualitative Investigation of Negative Symptoms in First-Episode Psychosis

Chapter Six – Lived-Experiences and Personal Understandings of Negative Symptoms in First-Episode Psychosis

6.1. BACKGROUND AND RATIONALE

6.1.1. Qualitative Research and Psychosis

The perspectives of those with severe mental health problems have, historically, been largely overlooked by researchers (Larsen, 2004). People with lived-experience of psychosis were rarely considered capable of actively contributing to understanding the disorder. Most psychosis research continues to be centred on the judgements of external observers who make ratings based on their assessment of participants' behaviour and responses to set questions. In such research, the investigator determines what is important about participants' experiences, largely ignoring how they themselves understand their experiences and what they consider to be important about them. In contrast, qualitative investigations of psychosis attempt to give precedence to participants' understandings and interpretations of their experiences. Such investigations – though still far outnumbered by quantitative studies – have become increasingly common over the past decade (McCarthy-Jones, Marriott, Knowles, Rowse, & Thompson, 2013). Together they provide a rich insight into the lived-experience of psychosis.

Aspects of psychosis that have received attention from qualitative researchers include the phenomenology of psychotic symptoms (Engqvist & Nilsson, 2013; Le Lievre, Schweitzer, & Barnard, 2011; Luhrmann, Padmavati, Tharoor, & Osei, 2015), the meanings attributed to psychotic symptoms (Hirschfeld, Smith, Trower, & Griffin, 2005; J. A. Larsen, 2004; Werbart & Levander, 2005), opinions of treatment received (Berry & Hayward, 2011; Lester et al., 2011; O'Toole et al., 2004; Tranulis, Goff, Henderson, & Freudenreich, 2011), barriers to accessing treatment (Anderson, Fuhrer, & Malla, 2013; Bay, Bjørnestad, Johannessen, Larsen, & Joa, 2016), the experience of stigma (Jenkins & Carpenter-Song, 2008; Knight, Wykes, & Hayward, 2003; Pyle & Morrison, 2013), and the impact of psychosis on identity (Dinos,

Lyons, & Finlay, 2005), relationships (Lloyd, Sullivan, & Williams, 2005; MacDonald, Sauer, Howie, & Albiston, 2005; Mackrell & Lavender, 2004) and occupational functioning (Krupa, Woodside, & Pocock, 2010; Lal et al., 2013; Nithsdale, Davies, & Croucher, 2008; Pondé, Peireira, Leal, & Oliveira, 2009).

McCarthy-Jones et al. (2013) synthesised the findings of 97 studies that used inductive qualitative methods to analyse the accounts of individuals with lived-experience of psychosis. Four superordinate 'meta-themes' were identified. The first meta-theme, 'Losing', encompassed losses encountered as a result of psychosis, including loss of a shared reality, loss of self, loss of relationships, and loss of hope and motivation. The second meta-theme, 'Identifying a need for, and seeking, help' centred on the process of accepting a need for help and seeking out that help: a process that can be hindered by reluctance to attribute experiences to illness and negative perceptions of mental health services. The third meta-theme identified, 'Rebuilding and reforging', concerned recovery from psychosis and identified rebuilding and reforging reality, self, hope, security and relationships as important elements of this process. The final meta-theme 'Better than new: gifts from psychosis' integrated themes of psychosis having a positive impact on the lives of participants. Such positive impacts included enhanced creativity and compassion, and improved family relationships.

The majority of the qualitative studies identified by McCarthy-Jones et al. involved participants given a diagnosis of schizophrenia who had been unwell for many years; studies of FEP were much less numerous. However, FEP is becoming an increasingly popular focus of qualitative enquiry. A systematic review carried out by Boydell et al. (2010) identified no studies based on first-person accounts of individuals experiencing FEP published before 2000, but 17 such studies published during the following decade. The findings of the review highlight the complex meanings individuals attribute to various aspects of the experience of FEP, including passivity and withdrawal, and the role of the social contexts in which young people live in shaping these meanings. Many studies of the lived-experience of FEP have

been published since Boydell et al.’s review concluded², suggesting that recognition of the value of qualitative research in understanding FEP continues to grow.

6.1.2. Qualitative Research and Negative Symptoms

Despite the recent growth in the qualitative literature on psychosis, negative symptoms have largely escaped the attention of qualitative researchers. None of the studies reviewed by McCarthy-Jones et al. (2013) or Boydell et al. (2010) focused specifically on the experience of negative symptoms. However, several studies have addressed topics and identified themes of relevance to understanding the lived-experience of negative symptoms. Le Lievre et al.’s (2011) investigation of the changing experience of emotional expression in individuals given a diagnosis of schizophrenia was one such study. The theme ‘experience of not being expressive’ is of particular relevance to understanding the experience of blunted affect and alogia. Reasons participants gave for staying silent included fears of being ignored or provoking negative reactions, and the belief that they would be unable to contribute to conversations due to perceived cognitive difficulties. Other participants explained that they chose not to speak because they felt slowed down as a side-effect of their medication, making conversations more difficult and less rewarding.

Another theme identified in Le Lievre et al.’s study, ‘experience of detachment’, is relevant to understanding asociality. This theme was evident in participants’ accounts of isolating themselves from others and an associated loss of emotional connection. Le Lievre et al.’s participants explained that making themselves emotionally or physically distant from others served to minimise their anxiety and protect their sense of self. Similarly, Krupa et al.’s (2010) study of activity and social participation following FEP found that young people described a lack of emotional connection, including a ‘deadening of emotions’, lack of pleasure, and loss of purpose, following their episode of psychosis. A mental health professional interviewed as part of the study suggested that participants’ professed loss of interest

²My literature search identified 34 qualitative studies of the lived-experience of FEP published between January 2010 and May 2015.

in previously valued activities may function as a coping mechanism, protecting them from the possibility of failure.

Boydell et al. (2003) conducted a qualitative study of diminished motivation in schizophrenia. While they chose not to frame the investigation as a study of negative symptoms, aiming to move beyond a narrow view of amotivation as a biologically determined symptom of schizophrenia, their findings are of relevance to understanding avolition. The study found that participants saw their motivation difficulties as a consequence of psychotic symptoms, concentration problems, depressed mood, medication side-effects, or others' low expectations of them. Participants discussed the stigma associated with low motivation, which is often perceived as laziness by others. Participants struggling with motivation, and consequently feeling excluded from society, often reported choosing to further isolate themselves in an effort to cope. However, participants also identified a number of more adaptive coping strategies, including having someone or something to care for, having someone to talk to, and building routine into their lives.

A further study that identified themes of potential relevance to understanding negative symptoms is Sandhu et al.'s (2013) exploration of depression following FEP. Participants expressed that emerging from acute psychosis and beginning to reflect on their experiences precipitated a downward spiral. Loss of established life roles and the break-down of relationships led to a 'crisis of identity', which manifested as low energy, pessimism and lack of motivation. Participants said that they became increasingly socially withdrawn due to a perceived lack of empathy, fear of further embarrassment in the event of relapse, or just not being in the mood to communicate with others. For some, struggling to keep up with college or work led them to stop these activities, which exacerbated their social isolation. Other qualitative researchers have found similar meanings to be attached to withdrawal following psychosis (Judge, Estroff, Perkins, & Penn, 2008; MacDonald et al., 2005; Mauritz & van Meijel, 2009).

These studies indicate the potential for qualitative research to offer insights into the lived-experience of negative symptoms and the personal meanings attributed to these experiences. However, these topics remain under-explored. Better understanding the lived-experiences of negative symptoms has the potential to offer insights into the complex psychosocial processes underlying these presentations, facilitating improved intervention. Thus the current study used qualitative methods to explicitly address how negative symptoms are experienced and understood by individuals with lived-experience of FEP.

6.1.3. Qualitative Secondary Data Analysis

Both the current study and the study described in Chapter Seven involved the secondary analysis of qualitative data. Qualitative secondary data analysis (QSA) is defined as the use of previously collected qualitative data to answer new or additional research questions, or to verify the findings of previous studies (Heaton, 2004). Whilst secondary analysis of quantitative data is a well-established research method, QSA has only relatively recently emerged as an acknowledged branch of qualitative research (Boydell, Gladstone, & Volpe, 2006). However, there is now a drive to encourage greater re-use of qualitative data (Irwin & Winterton, 2011). The Economic and Social Research Council (ESRC) strongly advocate the re-use of qualitative data, as evidenced by their policy of encouraging the researchers whose work they fund to make their qualitative data available for secondary analysis via their 'UK Data Service' archive (ESRC, 2015).

Qualitative data collection is resource intensive. As such, making maximum use of the resulting data has the potential to improve the efficiency of qualitative research. Since qualitative data are often extremely rich, it is almost inevitable that a single analysis will leave much of the data generated under-explored. Irwin & Winterton (2011) note several ways in which new insights can be generated from previously collected data. These include 'prioritising a concept or issue that was present in the original data but was not the analytical focus at that time' and selecting 'purposively from the sample used in the original study'. These strategies were used in tandem in

the current analysis: the analytic focus shifted from the evaluation of EIP services to the lived-experience of negative symptoms and a purposive subsample was selected to facilitate this change of focus.

6.2. RESEARCH QUESTIONS

1. To what extent do negative symptoms feature within participants' accounts of the experience of psychosis? How do participants describe the experience of negative symptoms?
2. How do participants understand and make sense of any negative symptoms they experienced?
3. Are there differences in the extent to which negative symptoms feature within the accounts given by those who followed differing negative symptom trajectories or the way in which the experience of negative symptoms is described?

6.3. METHOD

6.3.1. Design

The study employed QSA of the transcripts of interviews conducted with members of the EDEN cohort. Participants were interviewed up to three times about their experiences during their time with EIP services. The first interview was carried out towards the end of the participant's time with EIP or following discharge and subsequent interviews were conducted at yearly intervals. Interviews were semi-structured and focused on topics relevant to their experience of EIP, including psychosis, identity, relationships, recovery, and physical health. A purposive sample of negative symptom trajectory class members who took part in these interviews was selected for inclusion in the current study. Verbatim transcripts of the interviews were analysed thematically and comparisons made between the themes of interviews with those who followed differing negative symptom trajectories.

6.3.2. Setting

The individuals included in the current study were participants in the second phase of the EDEN programme: Super EDEN (see section 2.3 for further details). As part of the Super EDEN study, all participants were invited to take part in a qualitative sub-study exploring personal experiences of psychosis and EIP care. Participants who chose to take part in this sub-study were interviewed at yearly intervals during the two year follow-up period.

6.3.3. Data Collection

Topic guides for the interviews (Appendix C) were devised by the Super EDEN research team, led by medical anthropologist Dr Anna Lavis, in collaboration with the Super EDEN Lived Experience Advisory Panel: a panel of young people with first-hand experience of psychosis. Topic guide development was an iterative process in that later topic guides were updated to reflect themes participants guided interviews towards in earlier interviews. The initial topic guide was relatively structured. Later topic guides were less structured, offering participants a choice of possible topics to focus on during the interview. Topic guides were not intended to be prescriptive and interviewers were encouraged to follow the course set by the participant where possible in order to facilitate a free-flowing narrative. This approach was motivated by a desire to prioritise those issues deemed important by participants rather than imposing the interests of the researchers.

Interviews were conducted by study Research Assistants³ (graduates in psychology or another relevant discipline) working alongside the participating EIP services. All interviewers were trained in qualitative interviewing by experienced qualitative researchers. Interviews were conducted in the participant's home or an alternative venue convenient for the participant (e.g. their GP practice or mental health service

³ I personally conducted 28 interviews as part of the Super EDEN qualitative study.

base). Interviews were designed to take approximately one hour but varied in length depending on the level of detail participants chose to provide. Interviews were audio-recorded and transcribed verbatim by a professional transcription company⁴. These interview transcripts were the data for the secondary analysis.

6.3.4. Sampling Strategy

The sampling frame comprised 162 participants, each of whom participated in at least one Super EDEN qualitative interview. Further, these participants were included in the study described in Chapter Four and their trajectory class was calculated on the basis of complete PANSS data at two time points or more.

From within the sampling frame, a purposive sample was selected for inclusion in the current study. The sample was selected to maximise variation in key demographic variables including gender, ethnicity and study site. The proportion of participants selected from each of the negative symptom trajectory classes mirrored the relative size of the trajectory classes within the EDEN cohort as a whole. Since the majority followed the Minimal Decreasing trajectory, not all of those from this trajectory class selected during the initial sampling were included in the final analysis: the analysis was concluded once no new themes were identified through the analysis of an additional participant's transcripts (i.e. once saturation was reached).

This sampling strategy was intended to produce a dataset of a manageable size for qualitative analysis. Clearly it would not have been feasible to include transcripts from all 162 participants in the analysis while achieving the depth of analysis necessary to successful qualitative research. However, it was also considered important to include a sufficiently diverse range of participants from each negative symptom trajectory class; only by capturing a broad range of experiences would comparing the experiences of members of different classes be meaningful. The final sample included 24 participants who took part in a total of 57 interviews. Seven

⁴ A very small number of participants expressed that they would prefer their interviews not to be audio-recorded and in such cases the interview was transcribed in situ by a second Research Assistant.

participants were members of the High Stable or Mild Stable negative symptoms trajectory class, six were members of the High Decreasing class, and eleven were members of the Minimal Decreasing class.

6.3.5. Analysis Plan

The analysis took an inductive thematic approach (Braun & Clarke, 2006, 2013; Notley, Green, & Marsland, 2014). Thematic analysis is a method of identifying and recording patterns of meaning, or ‘themes’, in qualitative data in order to organise and describe the data in a way that answers the research questions posed. This method is appropriate for relatively large datasets and allows for categories to be data-driven rather than imposed on the basis of theoretical assumptions. The transcripts were grouped by negative symptom trajectory class and each group analysed independently before comparisons between groups were made.

Due to the small number of potential participants from the High Stable negative symptom trajectory class, the High Stable and Mild Stable classes were treated as a single group in the analysis. Thus the experiences of three groups were compared: the ‘Elevated’ negative symptoms group (members of the High Stable or Mild Stable latent classes), the ‘Decreasing’ negative symptoms group (members of the High Decreasing latent class), and the ‘Minimal’ negative symptoms group (members of the Minimal Decreasing latent class).

The thematic analysis followed the five phase procedure described by Braun & Clarke (2006): (1) familiarisation; (2) initial code generation; (3) searching for themes; (4) reviewing themes; and (5) defining and naming themes. The first phase – familiarisation – involved reading each of the transcripts carefully and noting initial impressions. The second phase – initial code generation – involved re-reading each transcript and dividing the text into small meaningful segments. Each segment was labelled in a way that attempted to capture the semantic meaning of the unit, using the participants own words if possible. The third phase – searching for themes – involved organising the codes generated in the second phase into themes

representing patterns within the data. This process was aided by the creation of a documents summarising the thematic content of each participant's transcripts.

Once a set of possible themes had been devised, the fourth phase – reviewing themes – began. This phase was an iterative process involving revisiting the data supporting each theme, adding, removing, subdividing or collapsing themes where necessary, before returning again to the data. The aim during this phase was to ensure themes were sufficiently coherent to form a meaningful unit whilst being sufficiently different from one another to be clearly distinct. At this stage, differences and similarities between the themes developed for each of the negative symptoms groups were explored and common themes amalgamated into one overarching theme where appropriate. In the final phase, themes were named to communicate the essence of each theme and, taken together, the overarching story of the analysis. Verbatim quotes to be included in the presentation of the study's findings were selected on the basis of their suitability as illustrations of the analytic themes developed.

The qualitative data analysis software package NVivo (Version 10; QSR International, 2012) was used to assist the analysis process. Initial coding was completed by hand using hard copies of the transcripts. NVivo was then used to organise the codes generated into possible themes, and to review and refine these themes. It was also used to organise the documents summarising participants' transcripts and memorandums documenting the analytic process.

To enhance the credibility of the analysis, a small number of transcripts were selected at random⁵ to be subjected to independent analysis by a second researcher. The researcher was kept blind to the negative symptom trajectory of the participant who gave the interview. This process was intended to substantiate that the study's findings were rooted in the data analysed, and not unduly influenced by knowledge of the participant's negative symptom trajectory class membership. The researcher who carried out the independent analysis is a clinical academic and a qualified

⁵ The online random number generation service provided by www.random.org (operated by Randomness and Integrity Services Ltd.) was used to facilitate random selection of transcripts.

clinical psychologist, with expertise in early psychosis. The independent analysis converged with the emerging themes of the primary analysis, lending credibility to the claim that the themes generated were firmly grounded in the accounts of the study's participants.

Nearly all included participants took part in more than one interview, and thus there was the opportunity to observe longitudinal developments in participants' views and interpretation of events. While changes in participants' accounts over time were considered during the analysis, their limited relevance to the study's research questions led to a decision to present the findings as if the data were cross-sectional. Given the already relatively complex comparative analysis, it was felt that including discussion of longitudinal developments in individual narratives would over-complicate the presentation of the results, obscuring the central findings.

6.4. RESULTS

6.4.1. Participant Characteristics

Demographic characteristics and negative symptom severity scores of the 24 participants included in the current analysis are presented in Table 6.1. Participants are referred to using pseudonyms throughout to maintain their anonymity.

Table 6.1. Sample characteristics by negative symptom trajectory group.

	Pseudonym	Study Site	Ethnicity	Age at Initial Interview	Mean Negative Symptom Score		
					BL	6M	12M
Elevated Negative Symptoms	Daniel	Norfolk	White British	20	4.00	4.43	4.00
	Max	Cheshire	White British	27	4.00	3.43	2.71
	Nathan	Birmingham	White British	26	3.43	3.29	2.57
	Yasmin	Lancashire	Asian Pakistani	28	1.57	3.29	2.57
	Tom	Cambs.	White British	20	1.71	2.29	2.14
	Hayley	Cornwall	White British	28	3.00	2.86	2.86
	John	Birmingham	White British	31	2.57	3.00	2.57
Decreasing Negative Symptoms	Jacob	Birmingham	Black Caribbean	28	3.43	3.43	1.00
	Aisha	Birmingham	Asian Pakistani	28	3.29	2.00	1.43
	Oliver	Cornwall	White British	30	3.14	1.29	2.00
	Stacey	Cornwall	White British	27	4.29	2.29	1.29
	Aidan	Norfolk	White British	25	3.00	3.43	2.14
	Steve	Lancashire	White British	27	2.86	3.71	2.14
Minimal Negative Symptoms	Philip	Norfolk	White British	37	1.00	1.29	1.29
	Nazir	Lancashire	Other Asian	21	2.29	2.29	1.86
	Alexander	Devon	Other White	32	1.00	2.57	1.00
	Shelly	Birmingham	Black Caribbean	28	1.29	1.57	1.29
	Isabella	Cambs.	White/Asian	35	1.57	1.14	1.14
	Jennifer	Lancashire	White British	30	2.14	1.57	1.00
	Ben	Birmingham	White/Caribbean	27	2.43	1.57	1.14
	Kelly	Norfolk	White British	22	1.43	1.57	1.71
	Clara	Cornwall	White/African	30	2.14	1.00	1.00
	Jack	Cambs.	White Irish	29	1.71	1.00	1.00
	Callum	Cheshire	White British	27	1.14	1.00	1.00

6.4.2. Thematic Analysis

The term ‘negative symptoms’ was used on just one occasion during the interviews analysed. During an interview with Jennifer – a member of the Minimal negative symptoms group – she remarked that she didn’t experience ‘*them negative symptoms that you get with schizophrenia*’. This remark was made in the context of explaining that she considered herself to be less in need of support than individuals with ‘*really really bad schizophrenia*’ who she believed to be at risk of self-neglect, depression, and misuse of alcohol or drugs as a result of not having ‘enough anxiety’. For Jennifer, negative symptoms were a marker of severity and stating that she did not experience them offered a means of distancing herself from those she perceived to be more unwell than herself.

Whilst the term ‘negative symptoms’ featured in the transcripts only once, descriptions of experiences corresponding to the negative symptom construct featured in the accounts of the majority of participants from all negative symptom trajectory groups. Descriptions of lack of motivation and withdrawal were very common features of the analysed accounts, appearing in the transcripts of 20 out of 24 participants’ interviews. References to diminished expression were less common, featuring in nine participants’ interview transcripts.

There were no notable differences in the extent to which accounts of difficulties with expression, social withdrawal or lack of motivation featured in the interviews given by individuals with differing negative symptom trajectories. Reports of lack of motivation and social withdrawal symptoms were most common in the transcripts of interviews with members of the Elevated negative symptoms group, but accounts of expressive deficits were more common in the transcripts of interviews with members of the Minimal negative symptoms group. There were also no group differences in themes related to the experience or understanding of negative symptoms identified. However, the analysis revealed a number of commonalities across all groups in the way negative symptom-like experiences were described and understood.

‘Like a zombie’

Several participants recounted difficulties interacting with others during their episode of psychosis. Participants often mentioned that they did not talk as much as was usual for them and some described being unable to express appropriate emotions. The simile ‘like a zombie’ was used by several participants when describing these experiences.

I wasn't moving, I was sitting down ... I wasn't talking. I was just like, you know, like a zombie, just sitting there ... I'd just sit down and not interact with anyone.⁶

Aisha, Birmingham – Decreasing Negative Symptoms

Before I was just sitting all day and not speaking at all and not showing any reaction when people were talking to me and stuff like that ... I didn't even like say anything when my sister had a baby. I wasn't even interested. I was just like a zombie and everything

Jennifer, Lancashire – Minimal Negative Symptoms

Through the use of this simile, the participants powerfully evoke the sense of otherness they experienced as a result of their difficulties interacting; it seems that participants felt remote not only from other people, but also from themselves. This self-alienation is exemplified by Callum's statement that he was not himself whilst he was in this zombie-like state.

I'm a zombie. Like when I'm walking around. People ask me questions and I'm like 'err' ... I'm not me.

Callum, Cheshire – Minimal Negative Symptoms

Thus for some participants, disruption in the ability to interact as usual appears to have led to a discontinuity in their identity. This is perhaps unsurprising given the importance of social performance to the construction and maintenance of identity.

Diminished internal experience

In a small number of cases, participants expressed that their diminished expression reflected reduced internal experience, that is, they reported that they were unable to talk due to a decrease in their ability to think, or failed to express the emotions expected of them because of decreased emotional intensity. For instance one

⁶To improve ease of reading, nonverbal utterances by the researcher (e.g. hmm, uh-huh, yeah) are omitted from quotations. Nonverbal utterances by participants are presented as transcribed. Where other material has been omitted, this is indicated by an ellipsis.

participant, Clara, explained that she was unable to communicate because she felt 'numb' and like her head was 'blocked'.

P⁷: I couldn't really communicate with anybody. Erm it's difficult to describe myself.

R: Did you feel locked in? Or?

P: I didn't feel like detached. And I, I didn't feel like anything.

R: Sort of empty? Or?

P: Yeah. Erm numb. Blocked. My head was sort of blocked. I couldn't think, therefore couldn't speak, because I didn't know what to say.

Clara, Cornwall – Minimal Negative Symptoms

For Jennifer, a lack of emotional expression was symptomatic of a long-standing inability to experience any strong emotion other than anxiety. Jennifer illustrated her account of the experience of diminished emotion by describing her indifference towards the events of September 11th.

I'd been not been able to have any feelings or anything and just like except to have feelings of anxiety but I didn't have feelings like that. Do you know that twin towers, when it crashed, I didn't care. I sat watching it, I was like, oh yeah boring. But now, when I watch programmes on it, I was nearly crying because I was like oh it's so dramatic and emotional and everything. But I remember distinctly when it happened, I just sat there staring and I was just like, I'm just not interested in that ... I didn't have any feelings for any of it. It was horrible. It was like I'd been possessed by a demon or something, it was really weird. It was like I wasn't even in my own body.

Jennifer, Lancashire – Minimal Negative Symptoms

Similarly, some participants explained decreased motivation as a consequence of a reduction in their drive and enthusiasm. Isabella gave a particularly moving account of such reduced drive.

⁷'P' is used to indicate words spoken by a participant, and 'R' to indicate words spoken by a study Research Assistant.

Before this happened to me I was always right let's do this, let's do that, right we'll get this plan and we'll do this, now I'm more kind of ... I'll get the Play Doh out and sit with my son even if I don't want to and I'll enjoy it but ... it's harder for me to enjoy those kinds of things because you do feel like you've had so much sucked out of you that, it's like that inner child it's a bit like someone's taken it by the neck, strangled it, it's just survived and then shaken it again and then said, right your life's never going to be the same again ... we go to the park, we go out for lunch, we go into town and go to groups or whatever and I do do that but just not with as much gusto as I did before.

Isabella, Cambridgeshire – Minimal Negative Symptoms

Such accounts align with traditional psychiatric definitions of blunted affect, alogia, avolition and anhedonia, which take reductions in expression and activity to be indicative of limited emotional range, reduced capacity for thought, lack of drive and reduced hedonic capacity. However, diminished internal experience was described by only a minority of participants who reported reductions in expression, motivation and sociability. More often, participants indicated that their capacity for thought and emotions remained intact and explained reductions in expression and activity in other ways.

Medication side-effects

The explanation for diminished expression, motivation and sociability most frequently given by participants was that these experiences were – or indirectly resulted from – side-effects of prescribed medication. Participants often commented that the sedative effect of antipsychotic medication decreased their drive to engage in activities requiring relatively more effort and energy. For instance, Isabella spoke about being less motivated to go to the gym due to the sedative effect of her medication.

You don't feel as motivated to get up and do things as perhaps I think I did before, more likely to go to the gym before I got ill than I am now because all I want to do, all the medicine really makes me want to do sometimes is just kind of, even though it's low dose, is just sort of curl up and be quite sedate really which obviously is the idea of it really.

Isabella, Cambridgeshire – Minimal Negative Symptoms

Another participant, Hayley, discussed the trade-off between the positive effects of sedation on her positive symptoms and the negative impact of sedation on the ability to socialise and participate in activities outside the home.

And because my thoughts were racing in really weird directions, they thought that a more sedative tablet would be better for me. But, of course, then that meant that I wasn't going out very much. I wasn't socialising. I wasn't really doing the things that may have helped me, you know, in the other part, the not medication part.

Hayley, Cornwall – Elevated Negative Symptoms

Although the medication Hayley was prescribed helped control her unusual thoughts, its sedative effect decreased her ability to socialise and participate in activities that might have aided psychosocial aspects of her recovery.

The experience of feeling 'like a zombie' was often, but not always, linked to medication side-effects. For Aisha, a change in her medication led to a dramatic increase in her ability to express herself, allowing her to reassert her identity as someone who likes to talk.

Actually I'm really happy with that because like even my mum says, 'You talk too much,' [laughs] but I feel like I've gone from not talking. I like to talk.

Aisha, Birmingham – Decreasing Negative Symptoms

For some participants, lack of motivation was not seen as a direct side-effect of medication, but the result of medication-induced weight-gain. This is illustrated by Aisha's description of the impact of her rapid weight-gain triggered by use of antipsychotic medication.

I feel like the heavier I am, the more harder for me to move around. And when I was lighter I was more active and doing loads of things and I had motivation and everything. And now like - my motivation - like before I had loads of motivation. Now that my motivation isn't really there. It's like someone has to push me to do things. Give me that extra support.

Aisha, Birmingham – Decreasing Negative Symptoms

Similarly, Hayley described a vicious cycle sparked by medication: the medication led to weight-gain, which lead to her feeling down, which lead to low energy, which lead to inactivity, which lead to further weight gain.

P: I didn't have one item of clothing that would fit me, well, other than my socks. Everything else didn't fit. Erm, even shoes were too tight, erm, everything, from pants to t-shirts, jumpers, coats, nothing fitted me. Erm, that was just, it was awful.

R: So then that contributed to you feeling more low and...

P: Yeah, and therefore not going out as much, and that, then, lack of energy, lack of doing anything [inaudible].

R: Was just a vicious circle, really?

P: Yeah, yeah.

Hayley, Cornwall – Elevated Negative Symptoms

'A confidence thing'

Lack of confidence in their abilities was another explanation participants gave for difficulties expressing themselves, socialising and maintaining motivation. One participant, Yasmin, describes how her experience of psychosis undermined her confidence in her ability to interact with others.

Yeah, and it's funny, oh, I mean I don't talk to anybody that much and I haven't got confidence left in me, because I think, 'Oh, my God.' I'm not sure about things which I'm doing. Like, am I not, am I doing right or not, because, you know, like, when you're unwell, you don't realise, do you? So it made me think, like, I've got no confidence, like, I don't know if what I'm doing is right or wrong.

Yasmin, Lancashire – Elevated Negative Symptoms

Yasmin talked at some length about her experience of behaving in ways that she now regards as inappropriate having undermined her confidence in her abilities. She described crippling doubt about whether her actions are right or wrong. Later in the interview, when discussing her hopes for the future, Yasmin spoke about not making

plans for the future because she felt she wouldn't be capable of carrying them out successfully.

At the moment I can't plan much because I know I've got not that much capability to do things.

Yasmin, Lancashire – Elevated Negative Symptoms

An account given by John illustrates how lack of confidence can manifest as not 'feeling up to' participating in recreational activities. John's reluctance to participate in activities outside the home seems to have stemmed from him underestimating his capabilities. This lack of confidence manifested as a lack of energy and drive: as not feeling up to going out.

In the early days I wasn't going out the house at all basically and there was a group, a group of people that got you out doing activities, which I didn't really want to do them 'cos I didn't feel up to them but it was, because they were they, give me these things to do I kind of forced myself and I think that helped quite a lot. It gave me the confidence that I knew I could actually go and do these things, like go out to a coffee shop or go to a garden centre and, or go for a walk or something, like simple things.

John, Birmingham – Elevated Negative Symptoms

As John's confidence in his ability to successfully engage in simple activities increased, he became more motivated to leave the house and begin doing things he enjoyed. As John began to recover his confidence, his parents' confidence in how far they could push him also increased. John explained that his parents moved from '*tread[ing] on egg shells*' to nagging him to '*get up and go and do something*'.

Both Yasmin and John described a general lack of confidence in their ability to successfully engage in even simple everyday activities. For other participants, their lack of confidence was specific to a certain domain. For instance Clara discussed her reluctance to engage in 'intellectual' conversations as a result of reduced confidence in her intellectual abilities.

I feel like I've lost a load of my knowledge. Erm and also I found it very difficult to learn again when I started to get back into things. I couldn't process information. So I feel like I've lost out on like ten years of learning. So now I'm with other 30 year olds and 40 year olds, even mid-20s, 20 year olds, and they know more than I do, and I can't - erm so I kind of - rather than sit down and have an intellectual conversation with someone, that scares me because I feel like I don't know. And perhaps that's a confidence thing. I know things that they don't know perhaps, but it just seems like I don't have that, that way of being able to process information or to capture the - to have that information that I had before.

Clara, Cornwall – Minimal Negative Symptoms

Although Clara was able to concede the possibility she might have knowledge that others do not, the belief that she no longer has the ability to process information in the way she once did prevented her from engaging with others she perceived as more intellectual. She noted that her place of work – a university – made this problem particularly acute.

Active avoidance

Participants often presented social withdrawal as a deliberate strategy, intended to protect them from rejection or ridicule. Several participants spoke about deliberately cutting contact with friends or making fewer efforts to form new friendships than they would have done before experiencing psychosis.

P: Do you feel that having gone through psychosis that's had an influence on your relationships with your family or friends in any way?

R: Erm yeah it's had an influence on my friends because when I had the psychosis and the problems I cut myself off from a lot of people, I withdrew and I lost a lot of friends through that.

John, Birmingham – Elevated Negative Symptoms

Isabella expressed that getting to know new people following her psychotic episode was a risk where before it had been an opportunity.

P: Perhaps not so, perhaps not so likely to take the risk to get to know a lot more people I think. I tend to sort of see what happens and go with that rather than sort of try and make more, try and widen my social circle by talking to more people, probably just let it happen now rather than make more effort.

R: And what's the worst that could happen then if you were to make more of an effort?

P: When you get instances where, you know, you'll talk to people and you just, you'll chat and you just sort of get the idea that they're, you know, they perhaps don't want to be as friendly as you'd like to be perhaps so it's all about sort of being a bit more, with relationships just being a little bit more...generally just letting things develop on their own really and not worry too much about it really. Whereas before I think perhaps I'd be a bit more keen to sort of get to know people better and perhaps be a little bit more intent on making friends I suppose in that way.

Isabella, Cambridgeshire – Minimal Negative Symptoms

Isabella went on to talk about putting ‘the boundaries up’ in order to protect herself from perceived social threat.

Since what's happened I don't really want too many people around, I suppose I yeah I've put the boundaries up and now I don't let so many people in and I'm happy with being, keeping things very narrow and not so broad ... That goes for family as well I don't, I mean my brother ... I don't let him get close enough to cause any trouble.

Isabella, Cambridgeshire – Minimal Negative Symptoms

Isabella was aware that this strategy had resulted in a narrower social circle and had distanced her from extended family but saw this as a price worth paying in return for avoiding ‘trouble’.

While Isabella was not explicit about why she perceived social situations to be more risky since her episode of psychosis, others linked their withdrawal to the stigma of having experienced mental health problems. For instance Ben explained that he withdrew from friendships due to the shame he felt.

My relationship with, erm, quite a few of my friends has changed in a negative way, and it's not been because of prejudice or lack of understanding on their part, it's because at first I felt very ashamed, and I deliberately cut them out of my life.

Ben, Birmingham – Minimal Negative Symptoms

Although Ben was clear that he was not subject to direct stigma regarding his mental health status, internalised stigma resulted in an intense feeling of shame which caused him to cease contact with friends. Participants were often acutely aware of negative media portrayals of psychosis and schizophrenia, which fed into their fears about how others would perceive them. Jennifer stated that the few '*vague friends*' she had '*wouldn't have been [her] friend no more if they knew [she] had a mental illness*'. Another participant, Aidan, who had lost contact with all of his former friends since experiencing psychosis expressed that he felt others would find him '*disgusting*' if he were to disclose his symptoms.

Shame and stigma were also key to some participants' decisions to avoid romantic relationships. Several participants shared the dilemma set out by Jennifer.

It'd be really really hard to establish a relationship because you wouldn't know when to say to them, 'I've got schizophrenia' because if you leave it too late, they'll say, 'Oh why didn't you tell me, you've led me on.' And if you say it too soon, they'd never even speak to you because they'll just assume you're mad and it's very very, that's very difficult.

Jennifer, Lancashire – Minimal Negative Symptoms

In common with several other participants, Jennifer felt she was trapped in a Catch-22 situation; whatever stage of a new relationship she chose to disclose her diagnosis of schizophrenia would be the wrong one: either too early or too late, both preventing the relationship from progressing any further. She had therefore ruled out the possibility of forming an intimate relationship and didn't believe she would ever be in a position to marry or have children. Definitions of negative symptoms frequently consider lack of intimate relationships in individuals with psychosis to be symptomatic of the loss of capacity for emotional closeness. Jennifer's account offers the alternative explanation that people with psychosis may have given up hope

of fulfilling their desire for an intimate relationship due to the perceived impossibility of establishing one.

Some participants employed an active strategy of avoidance in order to escape negative evaluation of their changed appearance following medication induced weight-gain. For instance, Clara explained that after her dress size increased from a size 12 to a size 22 following rapid weight-gain as a side-effect of antipsychotic medication she avoided social situations in order to protect herself from the critical gaze of others.

P: I think that [rapid weight-gain] gave me a lot of the anxiety I had from err not going out, not wanting to see anybody that I knew, because I had my episode and was in the ward in London, then came back down. No one knew what had happened to me, but I was huge and I wasn't talking to anyone.

R: Okay. So it made you more socially isolated?

P: Oh yeah. I didn't want anyone to see me like that. I know it's sad, but I really didn't.

Clara, Cornwall – Minimal Negative Symptoms

Stigma seems to have played an important role in Clara's decision to withdraw socially: she feared her sudden weight-gain would alert people to the fact that she had experienced mental health problems. In discussing the impact of her weight-gain she commented:

I think it is a quite big pressure on somebody that's already vulnerable to then give them the stigma ... because you then become, you don't really, you don't really fit anywhere any more.

Clara, Cornwall – Minimal Negative Symptoms

Given the context of this extract, Clara's use of the word 'fit' here suggests a double meaning: as she gained weight, not only did Clara no longer fit into her old clothes, but also into society.

Ongoing alogia?

While there were not notable differences in the extent to which negative symptoms featured in the transcripts of the groups compared, there were conspicuous differences in the fullness of the descriptions of negative symptoms provided. The descriptions of negative symptoms given by members of the Minimal group tended to be fuller than those given by the Decreasing group, which were in turn fuller than those given by the Elevated group. These differences were in line with striking differences between the interviews given by members of the three groups in terms of their length and the configuration of interactions between the participant and interviewee more generally. Interviews given by members of the Elevated negative symptoms group were notably brief and were characterised by participants taking short conversational turns and rarely taking the conversational initiative in comparison to members of the other groups. They were also less likely to introduce new topics or otherwise take the conversational lead than were other participants.

For example, compare the response given by Daniel, a member of the Elevated group, to the question ‘can you describe what things are most important to you at the moment?’ to the response given by Callum, a member of the Minimal group, to an almost identical question about the things that are most important to him. Although both participants answer that their family is the most important thing in their life, their answers are very different.

R: Can you, sort of, describe to me a bit about what things are most important to you at the moment.
P: Family and stuff like that, really.
R: Family and stuff like that, yeah.
P: Yeah.

Daniel, Norfolk – Elevated Negative Symptoms

R: Can you describe the things that are most important to you at the moment in life?

P: In life? Me dad, obviously, because he's got Motor Neurone's and me girlfriend, me brother [Name], because it's, like, we got brought up together; my other brothers, we didn't, you know what I mean. So he, if something happened to one of my other brothers I would be upset, you know what I mean, but if something was to happen to him, I would be, like, really upset, like, because the other brothers, I care because they're me brother, but at the end of the day it, they wouldn't really affect me, because I haven't lost someone that hasn't been there, because I lost them anyway, already [participants talking over one another].

Callum, Cheshire – Minimal Negative Symptoms

Whereas Daniel answers with just a few words, Callum is comparatively verbose and volunteers a great deal of detail. This example is representative of the way in which Daniel and Callum respond to questions throughout the interviews, and each are typical of their respective negative symptom trajectory groups in this respect.

The brief conversational turns and lack of conversational initiative displayed in interviews with members of the Elevated negative symptoms group might be interpreted as evidence of alogia. It is plausible, given that these participants followed a trajectory of stably elevated negative symptoms during their first 12 months with EIP, that this group were continuing to experience negative symptoms and were thus less able to express themselves during the interview. This possibility is discussed further in section 6.5.2.

6.5. DISCUSSION

6.5.1. Review of Findings in Relation to Research Questions

To what extent do negative symptoms feature within participants' accounts of the experience of psychosis? How do participants describe the experience of negative symptoms?

The term ‘negative symptoms’ featured in only one participant’s account of her psychosis, in the context of stating that she did not experience negative symptoms. However, descriptions of negative symptoms – including diminished expression, social withdrawal and lack of motivation – were given by members of all three negative symptom trajectory groups. The experience of negative symptoms was described by some participants as feeling ‘like a zombie’: some described being unable to react to events and other people as they usually would and so feeling disconnected from themselves and the world around them. A minority of participants described decreased internal experience – decreased emotion, thought or drive – during their psychosis.

How do participants understand and make sense of any negative symptoms they experienced?

Participants’ accounted for the diminished expression, social withdrawal and lack of motivation they experienced in a variety of ways, attributing divergent meanings to these symptoms. Whilst some participants put their negative symptoms down to decreased emotional range, capacity for thought or diminished drive, this explanation was not prevalent. Most participants’ personal understandings of the negative symptoms they experienced related to side-effects of psychiatric medication, lack of self-confidence and/or active avoidance in the face of difficult circumstances.

Are there differences in the extent to which negative symptoms feature within the accounts given by those who followed differing negative symptom trajectories or the way in which the experience of negative symptoms is described?

The descriptions of negative symptoms given by members of the Minimal group tended to be fuller (in keeping with the more expansive style of this group’s interviews more generally) but there were not marked differences between groups in terms of the extent to which descriptions of negative symptoms were a feature of participants’ accounts, or in the content of these descriptions.

6.5.2. Interpretation, Relevance to the Literature and Theoretical Significance

It might be suggested that the absence of the term ‘negative symptoms’ within participants’ accounts indicates that these symptoms are not acknowledged or deemed important by participants. Selten et al. (1998; 2000) found that inpatients diagnosed with schizophrenia gave lower ratings of the frequency and severity of their negative symptoms than did psychiatrists. They concluded from this that patients often underestimate the severity of their negative symptoms due to lack of insight. The absence of explicit mentions of negative symptoms within participants’ transcripts could be taken as evidence in support of Selten et al.’s findings. However, given that participants frequently described diminished expression, social withdrawal and lack of motivation, it seems likely that participants’ not having used the term ‘negative symptoms’ is indicative of a preference for natural, non-technical language rather than limited insight. In support of this interpretation, note that the term ‘positive symptoms’ did not feature in participants’ accounts at all. While participants did sometimes refer to having experienced ‘hallucinations’ or ‘delusions’, they were more likely to talk about seeing things, hearing voices and having had strange or paranoid thoughts.

That descriptions of negative symptoms occurred in the transcripts of interviews with participants from each of the negative symptom trajectory groups to a similar extent was unexpected. It was anticipated that experiences of negative symptoms would be most likely to feature in the accounts given by members of the Elevated negative symptom group, and would rarely feature in the transcripts of interviews with Minimal negative symptom group members. There are a number of potential explanations for this unforeseen finding. Given that the correspondence between self-reported experiential deficits and observed negative symptoms has been found to be limited (see section 1.4.2), it is possible that the subjective experiences of diminished expression, social withdrawal and lack of motivation reported by members of the Minimal negative symptoms group do not correspond to observable negative symptoms. Alternatively, it may be that these experiences did correspond to observable negative symptoms but that these occurred outside of the period during which participants’ negative symptom severity was measured. Under-

reporting of negative symptoms by the Elevated group might also be relevant in explaining this finding.

It was observed that the Elevated negative symptoms group's interviews were markedly shorter than those given by members of other groups and were characterised by short conversational turns by participants and a comparatively passive conversational style. A possible explanation of this finding is that participants from this group, who had previously presented with persistently elevated negative symptoms, were manifesting ongoing expressive deficits. Given that the interviews were, in most cases, conducted several years after the data used to determine the participants' negative symptom trajectory were collected, if this interpretation is accurate it would imply the longer-term stability of the trajectory of stably elevated negative symptoms observed during the first 12 months of EIP. Analysis of longer term follow-up data would serve to verify whether participants from the Elevated group did indeed continue to follow a trajectory of stably elevated negative symptoms, and thus whether this explanation is plausible.

Several participants in this study used the simile 'like a zombie' to describe experiences of having difficulties interacting with the world around them. In doing so they evoked a sense of otherness and alienation. Consistent with theories of the importance of social performance to the construction and maintenance of one's identity (Goffman, 1959), some described a discontinuity in their identity as a result of changes in their ability to interact with others. The participants' narratives highlight the challenge of maintaining one's sense of identity while experiencing symptoms that undermine the performance of this identity.

Participants' descriptions of their experiences of difficulties with communication and motivation suggests that European phenomenological approaches to psychosis may be of relevance to understanding the subjective experience of negative symptoms. The European literature on the phenomenology of schizophrenia provides perhaps the richest explorations of the experiential facet of negative symptoms (Bürgy, 2008). This literature suggests that negative symptoms are not straightforward deficit

states but are instead characterised by positive experiential disturbances stemming from core disturbances in the sense of self (Sass & Parnas, 2003). The findings of the current study support the contention that subjective experiences of negative symptoms are not always simple absences of something normally present. Instead, they can encompass positive experiential states that are not necessarily 'direct analogues of what is observed at the behavioural level' (*ibid.*, p. 433). The role of disturbances in the sense of self in negative symptom presentations was explored in a subsequent study (Appendix D).

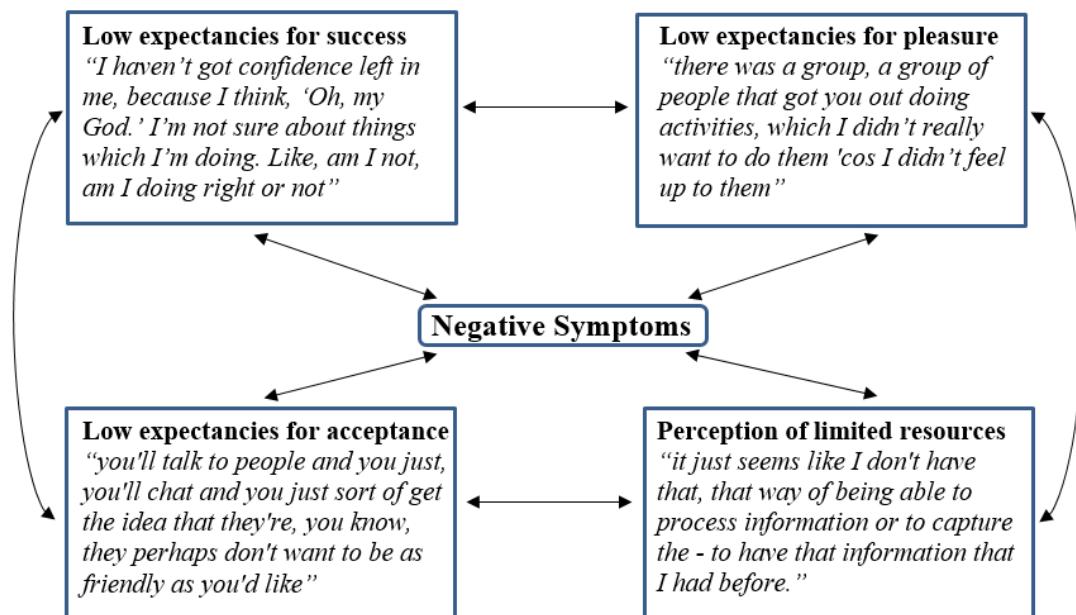
Participants offered varying explanations of the negative symptom-like experiences they described. Consistent with research carried out with individuals with more chronic psychosis (Boydell et al., 2003; Le Lievre et al., 2011), participants often believed that reductions in expression and motivation could be accounted for by the side-effects of psychiatric medications. Some participants described decreased emotional experience, capacity for thought or drive as lying behind changes in their behaviour. This finding echoes a theme identified by Krupa et al. (2010) who reported that individuals recovering from FEP described a deadening of emotions, apathy and reduced pleasure, turning participation in previously valued activities and social interactions into experiences to be endured. Participants also identified lack of confidence as a reason for negative symptom-like behaviour. Previous psychotic symptoms and the perception of decreased cognitive capacities undermined participants' confidence in their abilities, leading to decreased activity and interaction. This finding supports quantitative evidence that pessimistic assessments of cognitive and social capabilities may be implicated in negative symptom maintenance (Beck & Rector, 2005; Horan et al., 2010; Oorschot et al., 2013).

The theme 'active avoidance' corresponds closely with themes identified by studies that have explored social withdrawal following psychosis. A number of studies have described narrowing of social circles and increased isolation as deliberate strategies for minimising the risk of embarrassment, exposure to negative judgments, or lack of understanding (Boydell et al., 2003; Judge et al., 2008; Le Lievre et al., 2011; MacDonald et al., 2005; Mauritz & van Meijel, 2009; Sandhu et al., 2013). The difficulties engaging in new romantic relationships following psychosis highlighted

in the current study have previously been discussed by Redmond et al. (2010). In a study of the personal meaning of romantic relationships for young people with psychosis, the authors identified the theme 'illness as incompatible with relationships' encompassing dilemmas regarding disclosure of past psychotic episodes.

Participants' personal understandings of their experiences of withdrawal fit within the explanatory framework provided by the cognitive models of negative symptoms (see section 1.5.3). Facets of the lack of self-confidence described by participants can be aligned to the negative expectancies thought to be particularly relevant to the manifestation of negative symptoms by Beck et al. (Figure 6.1).

Figure 6.1. Cognitive expectancies proposed to contribute to negative symptoms illustrated by extracts from interviews with Aisha, John, Clara and Isabella (clockwise from top left). Adapted from Rector et al. (2005).



That many participants in the current study described negative symptom-like behaviour as an active coping strategy further supports a cognitive approach to understanding negative symptoms. Participants described avoiding social interactions and limiting their involvement in potentially challenging activities in

order to stave off failure, rejection or ridicule. This supports the contention that apparent emotional and motivational deficits are often underpinned by psychological processes that reflect active coping in difficult psychological and social circumstances. There were striking correspondences between the psychological factors proposed by Strauss et al. (1989) to contribute to negative symptoms and the narratives of some participants. For instance, Yasmin's account of limiting her interactions with others in order to minimise the possibility of doing or saying something inappropriate, as she felt she had during her episode of psychosis, closely resembles Strauss et al.'s depiction of withdrawal as a means of protecting oneself against public displays of bizarre or impulsive behaviour.

The relevance of perceived stigma to some participant's active avoidance supports the inclusion of negative self-perceptions, self-stigmatisation and expectation of social exclusion in Staring et al.'s (2013) cognitive model of negative symptoms. In line with Staring et al.'s model, shame and expectations of discrimination contributed to some participants choice to withdraw from former friendships and to limit attempts to establish new relationships. Awareness of negative portrayals of psychosis and schizophrenia were sometimes implicated in such withdrawal. This finding points to the importance of considering societal as well as individual factors when seeking to understand negative symptoms.

Taken together, participants' narratives suggest a role for agency in negative symptom presentations, countering the framing of negative symptoms as passive manifestations of diminished capacity. This alternative interpretation of negative symptoms as, at least in some instances, reflecting personal agency recalls the findings of an anthropological study conducted by Corin (1990). Corin compared individuals given a diagnosis of schizophrenia who were frequently re-hospitalised with those who were not re-hospitalised. She found that individuals who remained out of hospital were characterised by maintenance of a position apart from the social world, associated with an attitude of detachment. Corin characterised this detached position as 'positive withdrawal', a recovery strategy characterised by the deliberate maintenance of distance from normative social roles and relationships (Corin & Lauzon, 1992; Corin, 1990). On the basis of her study, she concluded that negative

symptoms ‘include behaviours or reactions that share some external features but that are associated with profoundly diverging meanings’ (Corin, 1990, p. 171), a conclusion substantiated by the findings of the current study.

6.5.3. Limitations

Since the study employed QSA, the data were collected without a focus on this study’s research questions; participants were not specifically asked about their experience of negative symptoms and this could be considered a major limitation of the study. Had the data been collected using an interview schedule designed to elicit material of relevance to the research questions, it might have been possible to gain further insights into the subjective experience of specific negative symptoms and participants views on their genesis. Given that participants were not specifically asked about negative symptoms during the interview, that they were not mentioned during some participant’s interviews cannot be taken as evidence that they did not experience these symptoms. It is plausible that those that did not mention these symptoms spontaneously may have attached different meanings to these experiences than did those who did, and that these divergent views were not captured by this study.

However, there are perhaps also advantages of the interview questions not having been focused on negative symptoms specifically. Allowing participants to speak about the aspects of their psychosis they considered to be most important made it possible to observe the extent to which participants chose to prioritise negative symptoms within their narratives. It also allowed the explanatory frameworks participants employed to talk about negative symptoms to be observed. An interview schedule centred on negative symptoms would likely have primed participants to focus on specific aspects of negative symptomatology and encouraged them to talk about them using explanatory frameworks specified by the researcher.

It was not the initial intention to consider interactional patterns within the interviews as part of the analysis. However, striking differences in the interactional styles of

members of the Elevated group relative to other participants became apparent during the familiarisation phase of the analysis. Given the inductive nature of the analysis, it was considered appropriate to include this finding as a result of the study. However, the methods used were not well suited to exploring the differences that emerged in the interactional styles of members of different negative symptom trajectory groups; thematic analysis is intended to identify and record patterns in the content of qualitative data, not patterns in interactional style. These could have been more fully explored through conversation analysis which allows for the detailed study of oral interaction (Ten Have, 1999). Such an analysis would require the re-transcription of the interviews in line with the conventions of conversation analysis in order to facilitate the consideration of the structure of utterances and characteristics of speech delivery.

The timing of data collection might also be considered a limitation of the study. Participants were interviewed for the first time towards the end of their time with EIP or following discharge, in some cases several years on from their initial episode of psychosis. It is possible that the period of time that had elapsed between their episode of psychosis and the interviews might have limited participants' ability to accurately recall what went on during that period of their life. However, the timing of the interviews also had some advantages. A period of time having passed since the onset of their psychosis might also have afforded participants more time to reflect on their experiences. Further, the timing of the interviews might also have meant fewer participants were prevented from participating by ongoing symptoms. For instance, one participant from the Elevated negative symptoms group commented that, had the interviewer met him at the beginning of his period of recovery, he would not have felt able to participate in a conversation.

An additional limitation of the study is that there was a relatively small pool of participants with high levels of negative symptoms from which to draw the subsample for this study. This was both because the proportion of the National EDEN cohort who were members of the High Stable and Mild Stable classes was comparatively small, but also because members of these classes, particularly members of the High Stable class, were less likely than members of other classes to

consent to take part in a qualitative interview. It is not surprising that those who had presented as withdrawn, amotivated or inexpressive often declined the opportunity to take part in an in-depth interview about their experiences. However, as a result it is likely that the experiences of some of those with the greatest negative symptom severity were missed.

Failure to capture the views of those with the most severe negative symptoms is a problem likely to confront any interview-based qualitative study of negative symptoms. This difficulty has perhaps contributed to the lack of qualitative negative symptom research to date. The design of the current study did at least allow for the views of some individuals who experienced the most severe and persistent negative symptoms to be captured. Future qualitative research might benefit from employing methods less dependent on potential participants' ability and willingness to engage in in-depth interviews, such as participant observation or analysis of written communication.

6.6. CONCLUSION

In a purposive sample of EIP service-users who presented with varied early negative symptom trajectories, phenomena corresponding to the negative symptom construct were found to be a common feature of participants' accounts of the experience of psychosis. Several participants used the simile 'like a zombie' to describe their experience of having difficulties interacting with and responding appropriately to the world around them. Participants often attributed negative symptom-like experiences to the side-effects of psychiatric medication, lack of confidence, and active avoidance as a means of self-protection. Participants' narratives challenge the widespread framing of negative symptoms as passive manifestations of diminished capacity.

Chapter Seven – Exploring the Lived-Experience of First-Episode Psychosis in Individuals with Differing Negative Symptom Trajectories

7.1. BACKGROUND AND RATIONALE

7.1.1. Overview

This study used qualitative methods to investigate the lived-experiences of those who followed differing negative symptom trajectories during their first 12 months of EIP treatment. The study described in Chapter Four identified a number of baseline predictors of negative symptom trajectories. However, it is likely that experiences a participant has during their time with EIP are also relevant to the course of their negative symptoms. Understanding differences in the individual lived-experiences of those who presented with differing negative symptom severity and persistence might provide clues to the factors that contribute to negative symptom development and persistence. Exploring such differences might also help explain why there is an association between an individual's early negative symptom course and their social recovery during the first 12 months of EIP treatment.

The study focused on four key aspects of participants' experiences: their understanding of psychosis, their accounts of the treatment they received, their understanding and experience of recovery following FEP, and the impact of the experience of psychosis on participants' identities. These topics of inquiry were chosen on the basis of their having been found to be important aspects of the lived-experience of FEP in previous qualitative research and because it was felt they may be of relevance to understanding differences in the experience of those with differing negative symptom trajectories. The topics were selected from amongst those that featured in the Super EDEN topic guides, and, as such, were aspects of psychosis considered important by individuals with first-hand experience of psychosis (see section 6.3.3). Since the aspect of the study focused on identity developed into a somewhat distinct investigation, and in the interest of brevity, this part of the study is

reported in a separate chapter which is included as an appendix to the thesis (Appendix D).

The remainder of this section summarises what qualitative research has already revealed about first-person understandings of psychosis, experience of EIP treatment and the process of recovery following FEP.

7.1.2. Understandings of Psychosis

Several researchers have investigated the way in which individuals make sense of what they have experienced in the wake of FEP. An ethnographic study conducted by Larsen (2004), found that EIP service-users actively engage in finding meaning in their experiences of psychosis, making use of explanatory systems made available to them through psychoeducation and wider ‘cultural repertoire’. Biomedical and psychological systems of explanation often featured alongside one another in participants’ narratives. Spiritual explanations were also important to some participants and were often held in parallel to biomedical explanations despite the apparent incompatibility of these explanatory systems.

Larsen found two strategies for making sense of the experience of psychosis to be evident among his participants. He related these contrasting strategies to McGlashan et al.’s (1975) distinction between two recovery styles: ‘integration’ and ‘sealing over’. ‘Integration’ refers to endeavouring to place one’s experiences within one’s wider life-history, and thus to accept the experience of psychosis as part of one’s identity. ‘Sealing over’ refers to attempting to forget about their experiences and separate them off from their wider life in an attempt to protect their pre-psychosis identity. He found that, while some participants embraced a single strategy throughout the study period, the majority moved between the two, influenced by their current social and therapeutic context, and stage of recovery.

Werbart & Levander (2005) followed a small group of people who had been admitted to a specialist centre for FEP over an 18 month period in order to track the

development of their 'private theories' related to their psychotic symptoms. They found that the basic elements of participants' theories remained remarkably stable over time but that more subtle elements of the theory tended to evolve and become more 'coherent'. Several participants pointed to difficult circumstances during early childhood as important to the development of their psychosis but none relied on a single event in explaining their experiences. Like Larsen, Werbart & Levander related their findings to McGlashan et al.'s (1975) recovery styles; they observed that while some participants attempted to integrate their unusual experiences into the narrative of their life, others saw their psychosis as a 'gulf' in this narrative. However, in contrast to Larsen's study, none of Werbart & Levander's participants articulated theories of their psychosis centred on a biomedical explanatory framework. This might reflect the psychoanalytic treatment context and the researcher's focus on idiosyncratic personal theories as opposed to broader explanatory frameworks.

7.1.3. Experiences of Treatment

Studies focusing on experiences of the treatment provided by EIP services, the majority of which have been conducted in the UK, have identified a number of common themes. All identified studies (Harris, Collinson, & das Nair, 2012; Islam, Rabiee, & Singh, 2015; J. A. Larsen, 2007; Lester et al., 2011; O'Toole et al., 2004; van Schalkwyk, Davidson, & Srihari, 2015) found service users' relationships with their key worker to be central to the experience of EIP. Participants described close, supportive and trusting relationships with their key workers, which were highly valued. All studies found participants' views of the treatment provided by EIP to be largely positive. Several studies found that participants saw EIP as a 'Gold Standard' service, set apart from, and superior to, other mental health services (Harris et al., 2012; Lester et al., 2012; O'Toole et al., 2004). A theme identified by a number of studies was that participants felt involved in decisions regarding their treatment and experienced a sense of agency in their recovery (Harris et al., 2012; Lester et al., 2012; O'Toole et al., 2004).

Most studies reported few negative experiences of EIP: the only negative theme reported by more than one study was that high staff turnover sometimes led to discontinuities of care (Islam et al., 2015; Lester et al., 2011). Due to the strong relationship between EIP service users and their key workers, staff changes were experienced as particularly unsettling. Other negative themes related to some participants perceiving the support provided by EIP as over intensive (Lester et al., 2011), and some black and ethnic minority service users perceiving a disconnect between the support they received from EIP and the spiritual aspects of their lives (Islam et al., 2015).

7.1.4. The Process of Recovery

Within the medical field, recovery is usually defined as returning towards a normal or healthy state, demarcated by the absence of symptoms and return to premorbid levels of functioning. However, since the symptoms of psychosis are often persistent and those who experience psychosis usually do not have the opportunity to reach their full functional potential before the onset of the disorder, the applicability of this definition of recovery to this field has been questioned. Led by service-user movements, an alternative conceptualisation of recovery, sometimes referred to as personal recovery, has been developed. There have been many definitions of personal recovery since the concept first began attracting interest in the mid-1980s but the definition proposed by Anthony (1993) is perhaps the most frequently cited:

... a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness. (Anthony, 1993, p. 527)

Within this conceptualisation, recovery is a process of moving towards living in line with individually determined values and achieving personally meaningful goals. Importantly, this process is not viewed as being contingent on the absence of symptoms.

Leamy et al. (2011) conducted a systematic review and narrative synthesis of descriptions of personal recovery from mental health problems. The aim was to develop a conceptual framework of personal recovery for use in recovery orientated research and services. The framework developed included five key recovery processes: connectedness, hope, identity, meaning and empowerment.

Connectedness refers to the importance of feeling supported by others, having relationships and being part of a community. Hope includes belief in the possibility of recovery, motivation to change and participation in hope inspiring relationships. Identity comprises rebuilding a positive sense of identity and overcoming stigma. Meaning encompasses both finding meaning in the experience of mental ill-health itself and in building a meaningful life outside of this. Finally, empowerment involves taking control over one's own life and focusing on personal strengths.

Recovery has been a popular focus for qualitative investigations of FEP. Echoing the first-person recovery literature, qualitative studies have found that individuals experiencing psychosis often hold a far broader view of recovery than the mental health professionals caring for them (Lam et al., 2010). Key elements of the process of recovery from FEP identified by qualitative studies echo several of the recovery processes included in Leamy et al.'s (2011) model. They include finding meaning in the experience of psychosis (Connell, Schweitzer, & King, 2015; Lam et al., 2010; Subandi, 2015; Tan, Gould, Combes, & Lehmann, 2014; Windell, Norman, Lal, & Malla, 2015), rebuilding relationships (Connell et al., 2015; de Wet, Swartz, & Chiliza, 2015; Eisenstadt, Monteiro, Diniz, & Chaves, 2012; Subandi, 2015), reforging a strong sense of identity (Connell et al., 2015; Tan et al., 2014), and regaining control and agency (de Wet et al., 2015; Eisenstadt et al., 2012; Henderson & Cock, 2015; Subandi, 2015; Tan et al., 2014; Windell et al., 2015). Both personal striving and external support – including both professional interventions and the support of family and friends – are seen by participants as necessary to recovery from FEP (Henderson & Cock, 2015).

7.2. RESEARCH QUESTIONS

1. Are there differences in the way those who followed differing negative symptom trajectories understood their experience of psychosis?
2. Do individuals who followed differing negative symptom trajectories give divergent accounts of the treatment they received from EIP services?
3. Are there differences in the way those who followed differing negative symptom trajectories understood and experienced the process of recovery?

7.3. METHOD

The method for this study was the same as for the study described in Chapter Six (see section 6.3). An identical set of transcripts formed the dataset and analysis proceeded alongside analysis for the previous study, following the same procedure.

7.4. RESULTS

The themes identified are presented under three subheadings corresponding to the study's three research questions: (1) understandings of psychosis; (2) experiences of treatment; and (3) the process of recovery.

7.4.1. Understandings of Psychosis

‘Just chemical imbalances in your head’

Participants were asked how they made sense of what had happened to them: what they believed caused their psychosis and what the experience meant to them. Some participants articulated a primarily biomedical explanation of their experiences. A number of participants, for instance John, viewed psychosis as an illness caused by imbalances in the brain's chemistry.

R: we've obviously talked quite a bit about psychosis, can you describe what psychosis means to you?

P: Err psychosis is a problem that occurs in the brain erm I'm not quite sure why, chemical imbalances or whatever

John, Birmingham – Elevated Negative Symptoms

Those who held biomedical beliefs about the origin of their psychosis often appeared to derive benefits from employing this explanatory framework. These benefits included minimisation of self-blame, expectation of parity of esteem with physical illness, and hope that symptoms might be successfully treated with medication. For instance, John expressed that adopting a biomedical explanation of his psychosis as 'just an illness' helped him accept that his mental health problems were not his fault

I guess the health professionals that I saw from Early Intervention they kind of made me realised that it's just an illness, it's, it's something that happens, it's just like getting a cold or like it's just an illness, it's not who you are really, it's, it's not your fault, it just happens to some people and I don't know, yeah.

John, Birmingham – Elevated Negative Symptoms

John's use of the phrase 'it's just an illness, it's not who you are really' suggests that adopting a biomedical understanding of his experiences also served to protect his pre-psychosis identity by distancing his true, 'real' self from the self who emerged as a result of the illness. Another participant, Nathan, described how coming to understand psychosis as a neurobiological illness helped him accept the possibility of a cure, giving him hope for recovery.

I guess when I first suffered from my mental illness, I thought it was incurable. You sort of thought there's nothing that can make you better and my understanding now is that's totally wrong, you know, it's literally just finding the right medication and getting people well again. I guess my understanding of mental illness is that it's a curable illness which is just literally down to the chemicals in your head, that's it.

Nathan, Birmingham – Elevated Negative Symptoms

Wholly or mainly biomedical understandings of psychosis were most often articulated by members of the Elevated negative symptoms group, as well as by several members of the Decreasing group. Although the explanations given by some members of the Minimal negative symptoms group included biomedical elements, these tended to form part of multi-level explanations incorporating psychosocial as well as biological precipitating factors.

'It starts with stress that's in your life'

Other participants expressed understandings of their psychosis rooted in the damaging effects of stress and adverse life-events. This was the explanatory framework favoured by most members of the Minimal negative symptoms group. For instance, Jennifer's personal theory of the origin of her psychosis centred on her having experienced a number of traumatic events.

I'd had a lot of traumas. I'd kept getting sacked from jobs over and over again. Erm, like, not sacked, but they'd say, 'Laid off,' and it meant sacked really, but you didn't get into trouble for it, so you just went back on the dole, and it was really stressful. So I've had a massive amount of stress in my life, all these things going wrong, and that had caused the depression. I'm pretty sure, if I'd just had a job and I'd been fine, and nothing had gone wrong for me, I'd never have got the schizophrenia.

Jennifer, Lancashire – Minimal Negative Symptoms

For Jennifer, difficult life experiences – including the absence of her father, bullying by peers and a series of redundancies – led to anxiety and depression, which escalated into paranoia and episodes of derealisation on account of her not receiving timely support. Similarly, Nazir attributed his psychosis to having been bullied at school and becoming depressed as a result.

P: Yeah I reckon that stress can cause mental health problems as well, stress, that's how I got my problems, mental health problems because other people, that's why I was saying I've not got schizophrenia because type of people that get schizophrenia normally, people who have done drugs, I've never done drugs in my life because obviously it's against my religion ...

R: So you feel as though stress caused your mental health difficulties?

P: Stress caused my mental health, yeah. Because I was going through a bit of bullying in school and I was getting stressed and depressed and that's when my problem came.

Nazir, Lancashire – Minimal Negative Symptoms

While Jennifer accepted her diagnosis of schizophrenia despite not viewing her problems as biologically driven, Nazir believed a diagnosis of schizophrenia to be incompatible with his understanding of the nature of his problems. Nazir distanced himself from the ‘type of people that get schizophrenia’, perhaps as a means of protecting his identity from the stigma associated with schizophrenia.

Isabella was another participant who attributed her mental health problems to stressful circumstances. She described how the stress caused by problem neighbours, in combination with a lack of social support, led to the development of her psychosis.

Stress, yes I feel that was definitely a trigger because obviously I had a stressful time with my neighbours and that is possibly what really started it all off so I'd say stress was definitely a major, major factor, um, and probably social isolation as well probably doesn't help. You know I didn't have a very good support group, I did, I have lots of friends but I always felt very tokenistic.

Isabella, Cambridgeshire – Minimal Negative Symptoms

As well as viewing social isolation as a contributor to her psychosis, Isabella spoke about withdrawing socially as a result of her psychosis (section 6.4.2; p.167). This suggests the possibility of a vicious cycle whereby the social isolation which follows psychosis might contribute to the genesis of future psychotic episodes.

While most participants drew links between the non-specific stress of adverse life-events and deterioration in their mental health, others made connections between the nature of particular adverse events they had experienced and the specific symptoms they later developed. For instance, Clara, whose symptoms included extreme self-consciousness and a belief she was being watched, felt these symptoms might be

connected to her experience of being looked at as a child. She explained that, as a child with Nigerian heritage growing up in rural Cornwall, she stood out from those around her and often attracted the attention of strangers.

Ever since I was a little girl, I remember people just to look at me. Like a lot of people in the small village I lived in were like, 'Oh, isn't she cute?' And I remember lots and lots of that. I also remember just like grown men just looking out, driving past and just staring at me. There wasn't necessarily a sort of like weird or negative, but always, always being looked at. And now I'm, I'm really paranoid. Really paranoid, self-conscious person.

Clara, Cornwall – Minimal Negative Symptoms

Jennifer also made links between her childhood experiences and the content of her psychotic symptoms. One of the unusual beliefs Jennifer held when she was unwell was that she was a reincarnation of Marilyn Monroe; she believed she was about to undergo a spontaneous transformation whereby she would take on the physical characteristics of the film star. In explaining why she developed this belief she referred to a traumatic incident during her teenage years.

The reason I got the obsession with her, is at, erm, school, it started at 14; I wasn't depressed until I was 14. And this lad who I fancied, er, pretended that he fancied me, for a joke, because everyone called me a geek. And they told me to go and meet him in this place, and they were all waiting, erm, to make fun of me when I went to meet him, and he wasn't really fancying [inaudible]. And then he came and said, 'Oh, I'd never fancy you, ugly, ugly.' And he fancied Marilyn Monroe. He had a picture of her on his little science book, and so I became obsessed with her, because that was. For some reason I still liked him, even though he'd done that to me [laughs], so I don't know why I still liked him. So I got obsessed with her. I thought, 'He likes her, she must be really good'.

Jennifer, Lancashire – Minimal Negative Symptoms

Jennifer also linked her experience of being rejected and humiliated by her classmates to unusual beliefs she held about romantic and familial relationships to high status individuals. She explained that she developed these beliefs as a way of transferring some of the 'status, authority, and power' held by these high profile individuals onto herself.

Some such narratives linking experiences and beliefs to psychotic symptoms are reminiscent of longitudinal formulations. It is plausible that experiences of psychological therapy might have played a role in the development of such explanations. Whilst participants did not explicitly attribute their explanatory accounts to understandings developed during therapy, many members who presented such accounts talked extensively about their experiences of psychological therapy. Among the most unequivocal indications of a link between a participant's understanding of their psychosis and their experiences of psychological therapy comes in the following section of an interview with Jack (emphasis added).

P: Would you maybe want me to explain why I get psychosis or?

R: Yeah, what do you think it's about, why do you think?

P: You get; well it starts, it starts really with like, stress that's in your life you know, like there's all different types of stresses like money stress or family or relationship you know ... and when you factor in my low self-esteem as well, you know, when it all kind of goes together and then, from family history as well, my family history you know, it just all kind of, goes together and I start to get paranoid thoughts you know, and they kind of escalate, they can be about like people and work, you know, oh they're leaving me to do all the work or my boss thinks I'm not doing a good enough job you know, and I would get, I would spend time going over and it would go round and round in my head and get more and more paranoid and then I think you just take it that, your own mind just takes it to the next level you know and think you're; with me I kind of think, *I'm not sure, I'm going to have to check with [Name of therapist]*, but I think kind of, I was having so many paranoid thoughts and so many different feelings and I almost needed to create something, to rationalise it, you know, like a big conspiracy theory you know, just explain the feelings that were going on, how bad I felt, you know, and I think that's basically my psychosis, you know.

Jack, Cambridgeshire – Minimal Negative Symptoms

Jack interrupts his account of the factors involved in the development of his psychosis to remark that he would like to seek corroboration of a particular element of his explanation from his psychological therapist. This suggests a shared development of the explanation. Indeed, Jack referred several times in his interviews to his psychological therapist's role in helping him to understand himself and his psychosis.

The relatively complex, formulation-like explanations provided by members of the Minimal negative symptoms group contrast with the less-complex explanations preferred by most members of the Elevated negative symptoms group. Members of the Elevated negative symptoms group were less likely to invoke psychosocial factors in explaining the development of their psychosis and where they did, these explanations were less fully developed. They rarely elaborated on the way in which the life events they described could have contributed to their psychosis, despite sometimes being prompted to do so by the interviewer.

7.4.2. Experiences of Treatment

‘You’ve got to learn to swim or you drown … the early intervention team was a nice set of armbands’

Participants were asked for their views of the support they received from the EIP service responsible for their care. The majority of participants from all three negative symptom groups were extremely positive about the service. Many participants appreciated the flexibility of support offered by the multidisciplinary team.

Participants valued the holistic nature of the support they were offered: for instance, assistance with practical difficulties not directly related to their mental health problem and facilitation of social activities. Staff were described as professional, friendly and caring. The following extract presents a view typical of the majority of participants.

R: And when you first started, what was your expectation or idea about Early Intervention?

P: I had no idea at all. It was literally, to me they were a piece of driftwood, just something to latch onto. I needed something.

R: Yeah. And did they explain to you who they are and what they do?

P: Yes, they fully explained what they offered and the other services they, you know, provided.

R: Yeah. And what was your impression of the service as, you know, as time went on, whilst you were with them?

P: Very impressive, very considerate, and very tailored to the user's needs.

R: Yeah. And how did you find the staff?

P: Friendly, polite and professional.

Ben, Birmingham – Minimal Negative Symptoms

Many participants considered the support they received from EIP to have been integral to their recovery. Aisha credited the support she received from Early Intervention with moving her from feeling life wasn't worth living to feeling she 'can do everything'.

R: Okay, um, say for example you were talking to another person now and they were just about to start with Early Intervention, and they asked you your opinion about it, what would you tell them?

P: I'd say it's really good, it's great. It's one of the best things that can help people move on.

R: It's good in what way?

P: It helps you to like be yourself again, like it helps you to get back to normal, like even though like you feel that like um, that you can't do anything and you're not like worth living anymore and things like that it helps in a way that like you feel that you can do everything, that you've gone back to normal.

Aisha, Birmingham – Decreasing Negative Symptoms

Although the majority of views expressed were positive, not all participants were satisfied by the care they had received from their EIP service. Negative views centred on services taking control away from participants, the over-emphasis of medication at the expense of psychological treatment options, and experiences of inpatient care, each of which link to themes that distinguished the three negative symptom groups.

'I would like to be able to make the choices which led to my recovery'

The extent to which participants expressed that they felt able to make choices and exercise control over the treatment they received varied across negative symptom groups. Most participants from the Minimal and Decreasing groups articulated that they felt very much in control of the treatment they received. These participants described being provided with a range of treatment options and being supported to choose the best options for their symptoms, social circumstances and personal preferences.

I liked the flexibility, and I liked the fact that once I'd come to a certain stage with the service, that they allowed me to trust my own instincts to a degree, as well, and, you know, there wasn't a case of, it was never a case of, 'Oh, you should do this. You should do that. You must do this to get better.' It was a case of, 'Well, let's sit down. What do you think would help?'

Ben, Birmingham – Minimal Negative Symptoms

It was kind of like the same with [EIP], they give you a lot of err, like kind of you're in charge you know it's, they put a lot of emphasis on what you want to actually do you know.

Jack, Cambridgeshire – Minimal Negative Symptoms

That's why I was actually quite happy 'cause I didn't feel like they were forcing the pills down my neck as in 'You've got to have them' like that. They were like 'Well, if you don't wanna take them', you, you know, what I mean, like there, there's other avenues to explore so yeah.

Callum, Cheshire – Minimal Negative Symptoms

Callum made clear that the EIP service's willingness to support him in reducing, and eventually discontinuing, his medication was crucial in maintaining his engagement with the service. He explained that, had the EIP service insisted he continue to take medication, he would simply have stopped taking it against their advice.

They didn't just, like I say, just, like, 'Do it,' you know what I mean, and then not give you a choice and stuff like that. Because at the end of the day, I didn't have to take it, I could have just turned round and went, 'Fine, I won't take it at all,' but they were, like, 'Okay, we understand. We'll lower your dose ... And then they was, like, and slowly they weaned me down and got me off it, rather than me in the end just turning round and going, 'Well, fine. If you're saying that...well, I just won't take it at all, because you can't force me, like that, so they had the right attitude.

Callum, Cheshire – Minimal Negative Symptoms

The service's support for his decision to stop taking medication resulted in a gradual titration of his dose under medical supervision. This experience contrasts with that of Hayley, a member of the Elevated negative symptoms group, who was not offered the same degree of control over the treatment she received.

P: I used to try and be off medication for at least a couple of months a year.

R: Okay, okay. And was that done in conjunction with your CPN [Community Psychiatric Nurse] and psychiatrist, or?

P: That was done, generally, on my own [laughs] ...

R: So, would you reduce your meds on your own or just stopped?

P: Just stopped.

R: Right, okay.

P: I know that's really unadvisable, but, erm, but, yeah, I just wanted to be back in control, and, erm, back in control of my life.

Hayley, Cornwall – Elevated Negative Symptoms

Hayley's desire to feel 'back in control' of her life took precedence over her understanding of the potential risks of sudden discontinuation of antipsychotic medication. As a result, she chose to stop taking her medication without the knowledge of the professionals involved in her care. The contrast between the experience of Callum and Hayley, highlights the advantage of service-users feeling supported to make decisions about their treatment, even when these decisions go against the advice of the professionals involved in their care.

Hayley was not alone amongst Elevated negative symptom group members in feeling that she had limited control over her treatment. Whilst most members of the

Minimal and Decreasing groups felt they could exercise choice over the treatment they received, members of the Elevated negative symptoms group often described choices being made for them, resulting in a sense of powerlessness.

R: Is there anything about service that you maybe don't like, about the early intervention team, maybe about the way they do things?

P: Sometimes it's controlling on you. Control. You have to obey their, and listen to them, what they have to say or what they have to do ... I've got a life but the thing is I haven't got a full control over it. Do you understand? And that sort of thing. My life is going and I'm just controlled under the team. It's horrible sometimes when you think about it. You want to do some other things and you don't want to be on medication, you want to live a free life but you can't.

Yasmin, Lancashire – Elevated Negative Symptoms

The frustration Yasmin felt at having to 'obey' mental health professionals is powerfully conveyed. Yasmin did not feel the professionals working with her shared her priorities: to have enough energy to do the things that were important to her and to retain sovereignty over her own life. Instead the EIP team's priority was to ensure she continued to take her medication as prescribed in order to prevent her psychotic symptoms re-emerging. Whilst Yasmin's frustration is initially directed externally this later transmutes into frustration at herself. She commented that she was 'letting them' interfere in her life due to her lack of self-confidence.

R: Do you feel, like, that people are interfering in your life now?

P: But I'm letting them, that's the thing, because, because of how I've got no confidence in myself, and I, and I, so...

Yasmin, Lancashire – Elevated Negative Symptoms

Where Yasmin clearly resented the lack of control she was able to exercise over her treatment, other participants appeared resigned to their lack of influence. For instance Daniel, having not had any choice in his medication during his time in hospital, felt he should just continue the status quo when responsibility for his care was transferred to EIP.

R: And do you feel like you had a choice over your medication or do you feel like you kind of have to go along?

P: I'd go along with it yeah, when I was in hospital I had no choice but to take the medication.

R: Yeah. And when you came out of hospital do you feel like you could have had a voice and an opinion in to your medication?

P: I could of but it's probably just best to take it.

Daniel, Norfolk – Elevated Negative Symptoms

It is unclear whether this resignation should be interpreted as stemming from relief at someone else taking responsibility for difficult decisions, or from powerlessness in the face of a system perceived as overwhelmingly powerful.

Whilst most participants saw being offered control over their treatment as a positive, Shelly – a member of the Minimal group who was encouraged to make choices about her treatment once under the care of EIP – expressed ambivalence at being expected to make decisions about her care.

P: When I was with home treatment team it was different, there was always someone saying let's do this [Shelly], let's do that, let's do this [Shelly], let's do that and then when I was with ... Early Intervention, it was different. It was - I was more in control of everything.

R: Okay, so.

P: So because I was more in control of everything, I was the one that had to say where this needs to be done or that needs to be done, and that's it really.

R: Do you think that was better, that you were more in control?

P: Well, yes and no.

Shelly, Birmingham – Minimal Negative Symptoms

She went on to explain that she would have preferred the EIP service to take some decisions on her behalf, in accordance with her best interests. This highlights the potential for some participants to perceive responsibility for decisions about their treatment as a burden.

Psychological therapy

An interesting difference between the negative symptom groups was the extent to which psychological therapy featured in the accounts of the treatment they received. Participants from the Elevated and Decreasing negative symptom groups rarely mentioned having received psychological therapy. When explicitly asked whether they received psychological therapy during their time with EIP, most said no. In contrast, most members of the Minimal negative symptoms group spontaneously brought up their experience of psychological therapy.

Participants who mentioned having received therapy usually expressed that the experience had been beneficial. Key benefits of psychological therapy described by participants included improved coping strategies and feeling less helpless.

P: I've felt more enabled, I've developed more coping strategies, I've developed more of an insight into things. And more importantly more of an acceptance things. Because I very heavily kicked against things. Up until about a year ago now actually. And.

R: Do you know, sorry, I was just going to ask you, is there a reason why you changed? Is there something that happened or is it just passage of time or?

P: It was, I think a lot of it was to do with the psychology and psychotherapy sessions.

R: Ah, okay.

P: Were very sort of important.

Ben, Birmingham – Minimal Negative Symptoms

R: Okay, did you find it helpful then that the CBT [Cognitive Behavioural Therapy] was erm - was offered to you at [EIP]?

P: Yeah, definitely.

R: In what ways, what did it help with?

P: Just with that other, with that other feeling like you don't have to feel helpless there is things you can do, you know.

R: Yeah, yeah. Yeah it gave you back that control?

P: Yeah, yeah.

Jack, Cambridgeshire – Minimal Negative Symptoms

Jennifer spoke in detail about the specific cognitive techniques employed by her therapist. For instance, she described how her therapist encouraged her to challenge her belief that she should kill herself if it was not possible for her to look like Marilyn Monroe.

There was a cognitive behavioural therapist called [name]. She was really really good and she did loads of good stuff where she talked about all these special techniques like ... I was saying I was going to kill myself if I couldn't look like Marilyn Monroe so they said, 'what about other girls? If you see this girl – point to someone like – do you think she should kill herself because she's not as good looking?' I said no. They said 'Do you think this person is like ugly or fat, or something different she should kill herself.' I thought no, and said, 'Well why would you think you should kill yourself?' And it really worked. That's just one of the things she said. She said millions of different special tricks.

Jennifer, Cambridgeshire – Minimal Negative Symptoms

Jennifer said that she continued to use the techniques she learnt during her CBT to keep herself well. Several other participants who had received CBT also commented that the techniques they were taught by their therapist continued to be of use to them in managing their symptoms or preventing relapse.

Only one participant, Isabella, expressed a negative opinion of psychological therapy. She explained that she did not feel CBT (the only model of therapy offered to her by EIP) was suitable for her as it required her to think of her experiences as symptoms.

I did get the impression on one occasion where he was trying to fit all my symptoms into one model, this what do they call it, er, cognitive behavioural model and I kept thinking there's only one problem with this it's taking your perspective of what's happened to me [inaudible] it's not taking it from my perspective and it was fundamentally wrong because I'm the one that's, I'm the one that's been through this, I know way more than you how this has affected me.

Isabella, Cambridgeshire – Minimal Negative Symptoms

For Isabella, who saw her psychosis as a spiritual experience, fitting her experiences into a CBT model involved denying the meaning she attributed to them. Since leaving

EIP she had sought out person-centred psychotherapy and reported that she found it beneficial 'just to have somebody sit there and appreciate from your perspective what it's like'.

Participants' accounts point to some potential explanations for the scarcity of references to having received psychological therapy by those with higher levels of negative symptoms. One possibility suggested is that participants presenting with negative symptoms were less likely to be offered psychological therapy; the participants' accounts suggest that at least some members of the Elevated negative symptoms group were not offered psychological therapy. For example, Yasmin made clear that she would like to have been offered therapy but was not.

R: Do you feel as though they could have helped you in any way; that the Early Intervention Service could have helped you in any way that would have been better, or from what you've just said?

P: Erm, probably, yeah ... They didn't, like, offer me, like, therapy and stuff, and they just, like, being, just getting me sectioned and, you know, giving you medication and things like that.

Yasmin, Lancashire – Elevated Negative Symptoms

Another possible explanation is that participants were offered psychological therapy but chose not to take it up, as was the case for Tom.

R: And was there anything whilst you were with [EIP] that you wish you could have explored further?

P: Erm I wish I'd gone through with sort of psychology aspect of things and just talked and tried - like regression or whatever it's called and just talked more and gained a better understanding, but that wasn't through them not making it available, that was through me not taking up on the offer.

R: Right, I see.

P: I was able to do it, it's just I chose not to at the time. I mean looking back at it I wish I had but I know I wasn't in a comfortable position to do it anyway.

R: You didn't feel ready?

P: Yeah. But it was there, it wasn't that I wanted to do it but they said no or they couldn't do it, it was that I wish I'd done it now in hindsight.

Tom, Cambridgeshire – Elevated Negative Symptoms

Tom turned down the offer of therapy as he was not in a 'comfortable position' to participate but, with hindsight, wishes he'd taken up the offer. This suggests that individuals experiencing high levels of negative symptoms might feel less able to engage in a psychological intervention. One Elevated negative symptom group participant who was offered psychological therapy and took up this offer expressed a belief that he was not ready to participate in a psychological intervention.

I don't think it was the right time. I think I was, I was in, I was too unwell when, when I had it before ... I think I'd be more open to it now. And I'm, I'm more able to discuss my problems. When, when I had psychology before I used to hardly talk. I used to find it hard to put a sentence together. Erm and a lot of the time it was just the psychologist talking to me. And she'd ask me questions and I just didn't feel like I could answer them.

John, Birmingham – Elevated Negative Symptoms

John reflected that his therapy took place too early in his recovery, at a time when he was not able to fully engage in the process due to difficulty expressing himself. He indicated that his difficulty talking has since largely resolved and he would now be more able to engage in a conversation. Nonetheless, during a later interview, John mentioned that his experience of therapy had some positive impact in the longer-term despite his difficulties engaging at the time.

I had psychology sessions and err a lot of the things we talked about didn't really improve straight away but I remember the things we talked about and even today like they help with some things.

John, Birmingham – Elevated Negative Symptoms

Experiences of hospitalisation

The majority of participants from the Elevated negative symptoms group spoke about having experienced inpatient care during or immediately before their time with

EIP. This was in contrast to members of the Decreasing or Minimal negative symptom groups who rarely spoke about having experienced inpatient care. In keeping with the general brevity of these participants' accounts, only a couple of the majority of Elevated negative symptom participants who mentioned having spent time in a psychiatric hospital spoke about this experience in any detail. Those who did discuss it in detail were in agreement that the experience was not a positive one.

Well I've been to [psychiatric hospital] and the first time I was there, it was horrible, it wasn't a great place to be. They had communal rooms, so you were sharing four to six people. They were people the same as me, who weren't very well at all so it's very hard to sleep or do anything so you're put on edge. The food wasn't great; there really wasn't much you could do there.

Nathan, Birmingham – Elevated Negative Symptoms

I don't like that environment and it's just, you can't do anything and then [inaudible] medication and it makes you lethargic, and you feel depressed and all sorts and I don't wanna go through that again. It's just a waste of life.

Yasmin, Lancashire – Elevated Negative Symptoms

The negative opinions of inpatient care expressed by Yasmin and Nathan were in accord with the views expressed by the minority of members of the other negative symptom groups who had spent time in a psychiatric hospitals. A particularly vivid description of an experience of inpatient care was given by Clara who spent six months on an inpatient unit in London.

The whole way it was done, and you go there and you, you know, and the, the activities that you do in there are really - just felt so flat ... It was every day the same. You just want to sleep, and you don't want to get up. And when you get up obviously you're hungry, so you go and queue with your tray and you get your slop on your, on your tray, and then you go and sleep on a PE mat, you know, with a sheet kind of thing. Erm and I, you know, I, you know, I just don't think that's probably the best. I don't think it was actually very good for me erm at all ... But the people in, in the ward just they, they didn't seem passionate about us and about what we were going through, and about helping us.

Clara, Cornwall – Minimal Negative Symptoms

Given Clara's description of the monotonous and lacklustre daily routine on the ward, and apparent indifference of the staff, it is perhaps not surprising that she describes not wanting to get out of bed. It is quite possible choosing to lie in bed all day rather than get up and participate in activities would be deemed indicative of avolition; this perhaps suggests a possible explanation for experiences of hospitalisation being more commonly mentioned by those who presented with more severe negative symptoms.

7.4.3. The Process of Recovery

High benchmarks for recovery

The majority of participants from all negative symptom groups considered themselves to be partially, but not fully recovered. Definitions of what it would mean to be fully recovered were idiosyncratic but most often centered on either absence of symptoms, increased social and occupational functioning, or a combination of the two.

Interestingly, members of the Elevated and Decreasing negative symptom groups tended to set higher benchmarks for recovery than did the Minimal negative symptoms group. Many participants from the Elevated and Decreasing groups expressed that they considered recovery to encompass complete remission of symptoms and/or securing full-time paid employment. In contrast, members of the Minimal negative symptom group expressed a willingness to tolerate residual symptoms and some limitations in functioning within their definitions of recovery. For instance, Jennifer gave the following definition when asked to explain what she understood by the term 'recovery':

I think it's, erm, being able to, erm, enjoy stuff in your day again ... being able to do part time work or voluntary work. Obviously, full time work would be the main thing, but I still think it's if you just do voluntary work, really. Er, being able to meet people and stuff, erm, and being able to not have symptoms all day, and stuff like that. Being able to, like, have, have a lot of the day, like, er, more than 50% of the day where you didn't have symptoms. That's what I'd say it was.

Jennifer, Lancashire – Minimal Negative Symptoms

Many of Jennifer's fellow Minimal negative symptom group members also expressed the view that full-time paid work and complete remission of symptoms are not necessary for a person to be deemed 'recovered'. For these participants, engagement in part-time or voluntary work and the ability to manage any ongoing symptoms was viewed as sufficient for recovery.

'It's a matter of coping'

Participants from the Minimal negative symptoms groups placed greater emphasis on the concept of coping than did other participants. These participants expressed that they anticipated they would continue to experience some symptoms indefinitely, thus their ability to cope with and manage these symptoms was of central importance. For instance, Philip expressed a belief that he would always experience psychotic symptoms but that he could recover nonetheless by learning to manage these symptoms.

P: I think I'll always have, erm, these experiences [hallucinations] but erm I think over time they'll become easier to manage and erm, yeah, not, not say I've become blasé about it but I just think erm yeah, over the course of time ...

R: Ok, so you feel that probably erm you'll continue to have the experiences, but that over time you'll be able to sort of better cope with them and [inaudible].

P: Yeah, that's right yeah, yeah.

Philip, Norfolk – Minimal Negative Symptoms

For participants who were no longer experiencing symptoms, confidence in the ability to cope with any future recurrence of symptoms reduced the fear associated

with the possibility of relapse. Isabella had experienced a second episode of psychosis following the birth of her son and so was mindful of the possibility of further episodes but stated that she was not worried about this possibility because she has the ‘skills to deal with it’.

R: I mean are there any concerns about feeling that way again?
P: ... I think as long as I’m in control of it I feel it’s not going to be a problem, like I say as long as I’ve got skills to deal with it I – I don’t think it would be a problem.

(Isabella, Cambridgeshire – Minimal Negative Symptoms)

Similarly, Callum, who was interviewed shortly after being discharged from EIP back to the care of his GP, was asked whether he had any concerns about no longer being under the care of EIP.

R: Do you feel safe though just being under the care of the GP now that kind of Early Intervention has gone away, I guess, in the last week?
P: No because they didn’t just like go ‘right see you later’ ... they’ve set up support and they’ve made sure that I am capable. Before they’ve gone off like, you know what I mean, sort of thing. And that’s what they’re there for. To give you the skills to cope with it yourself. That’s what it’s for so that it doesn’t happen again.

(Callum, Cheshire – Minimal Negative Symptoms)

Callum made clear that he felt equipped with the skills to cope with future symptoms and so no longer felt the need for the input of secondary mental health services.

‘Well, actually, I’m in control of this’

The equation of recovery with the ability to cope with ongoing symptoms fits within a wider theme of agency in recovery that was characteristic of the accounts given by members of the Minimal negative symptoms group. Several participants in this group described using the knowledge and skills they acquired during their time with the EIP service to actively promote their recovery. For instance, Jennifer spoke about using the awareness she developed during her CBT sessions to guard against

developing further unusual beliefs about her relationship with high status individuals.

P: I know when I'm getting it now, and I just go, 'No, you're getting it again.'

R: How do you know you're getting it?

P: Well, I started thinking this MP, like, erm, I started thinking, 'Oh, he's, he's sending me messages.' He was sending me messages on Facebook, wanting me to vote for him and stuff and, like, being friendly, because he's trying to make friends on Facebook with other people to get them all to vote for him. And I started thinking, 'Oh is it special. Is it just me and him?' you know, and all this lot. And I started thinking, 'No, it's because he's an' ... they've got status, authority, and power about them. And it's, like, you want to get a bit of that power or something, so you want them to like you so you're special, like, sort of, thing. Erm, and so I start thinking that, and I've stopped myself, I stopped that.

Jennifer, Lancashire – Minimal Negative Symptoms

Similarly, several participants from the Minimal negative symptoms group spoke about EIP empowering them. They described EIP services as helping them to understand themselves better and thus to make changes themselves, rather than professionals solving problems on their behalf.

It hasn't waved a magic wand and made everything better, but it's enabled me to understand things more. And when you understand things more they're not quite as intimidating, and so that in itself was quite empowering.

Ben, Birmingham – Minimal Negative Symptoms

In contrast, an apparently more passive attitude to recovery was evident amongst members of the Elevated, and to a lesser extent the Decreasing, negative symptom group. Compare the responses of two participants – Daniel, a member of the Elevated negative symptoms group, and Alexander, a member of the Minimal negative symptoms group – to similar questions about their role in creating a plan for identifying and dealing with any future deterioration in their mental health (known as a 'staying well' or 'relapse' plan).

R: So, are you saying that you've been shown a, sort of, staying well plan?

P: Yeah, I've been shown them, yeah.

R: But you're not saying you were that active in creating it?

P: No, not really, no, no.

R: Do you agree with what the plan says, or?

P: I can't really remember, to be honest.

Daniel, Norfolk – Elevated Negative Symptoms

P: Yeah, I have a relapse plan, and I devised something with the four pillar model.

R: Right, okay.

P: Where you imagine that you have four pillars, which hold up the roof, and the roof is the level playing field of your mental health, and if any one of the pillars gets too tall or too short, the roof becomes unstable and it slides ...

R: And did you see yourself as active in creating, creating it?

P: Yeah. It was, I was given the chance to develop whatever kind of relapse plan I thought was appropriate, and we did in fact, develop an appropriate relapse plan.

R: Excellent.

P: Okay. I think it's in my folder upstairs, last year's folder. I will just grab it and show you, before you go out the door.

Alexander, Devon – Minimal Negative Symptoms

Whilst Daniel recalled a relapse plan having been created, he didn't consider himself to have been an active participant in its creation. Perhaps because of his lack of active participation in its creation, he was unable to remember the plan's content. In contrast, Alexander seems to have been a very active participant in the creation of his relapse plan. His choice of the first-person singular pronoun in the utterance 'I devised something with a four pillar model' indicates that he viewed himself as the primary author of the plan. He expressed satisfaction with the relapse plan created, apparently recalled its content clearly, and was even keen to show it to the researcher. This is a particularly concrete example of a wider pattern of the relatively active approaches to recovery evident in the narratives of participants from the Minimal negative symptoms group.

Recovery contingent on medication

Members of the Elevated and the Decreasing groups often appeared quite passive in their attitudes to recovery when their accounts were considered alongside those of the Minimal group. Several Elevated and Decreasing participants expressed the view that their recovery was contingent on their continuing to take medication.

R: And do you have any fears of having another episode at all, is that something that bothers you?

P: Err I don't think I would as long as I'm on the medication.

R: Ok so you feel like as long as you're on the medication then that will be ok.

P: Be fine, yeah.

Daniel, Norfolk – Elevated Negative Symptoms

R: So do you feel in order to recover that you need to see psychosis as something separate from you or do you think that's not necessary?

P: Um, how can I explain it, psychosis, I suppose you have to see it as an illness you've had but I don't think you have to see it as part of you because you're taking tablets to stop it.

Nathan, Birmingham – Elevated Negative Symptoms

For such participants, medication compliance appeared to be what they considered to be their primary role in promoting their recovery. The belief that medication is primarily responsible for one's recovery leaves little room for personal agency. An Elevated negative symptoms group participant, Hayley, employed a metaphor of being driven through life in a horse drawn carriage to describe the reduction in agency she felt as a result of trusting her recovery to medication.

Whilst on medication it's as if – I always see myself in one of these – er, it's just one of my visual things – erm, like a horse-drawn carriage, and someone's, erm, driving. Erm, and you're just sitting there and you're watching everything, and the ride's nice and it's smooth, and you go through things, and they whisk you through bad places, good places, but you're not quite in control. And it's nice to think, 'Well, actually, I'm in control of this, and I'm gonna go the way I want to go', and I find that medication is that driver. So it takes you one step back from being in full control of your life.

Hayley, Cornwall – Elevated Negative Symptoms

7.5. DISCUSSION

7.5.1. Review of Study Findings in Relation to Research Questions

Are there differences in the way those who followed differing negative symptom trajectories understood their experience of psychosis?

There appeared to be differences in the way in which members of the different negative symptom trajectory groups made sense of their experience of psychosis. Participants who were members of the Elevated and Decreasing groups gave primarily biomedical explanations of psychosis: they tended to view psychosis as an illness caused by aberrant neurochemistry. Members of the Minimal negative symptoms group preferred psychosocial explanations of their experience; their understandings of the development of their psychoses generally gave stress and adverse experiences a central role. Members of this group often gave relatively complex accounts of how their psychosis developed and was sustained, often resembling longitudinal formulations.

Do individuals who followed differing negative symptom trajectories give divergent accounts of the treatment they received from EIP services?

Participants from all negative symptom groups expressed largely positive opinions of the service they received from their EIP team. Most participants from all three groups felt that the treatment they had received had been beneficial and were complimentary about the staff who delivered it. However, beyond this general approval, several differences emerged in the treatment members of the three negative symptoms groups described having received.

Participants from the Elevated negative symptom group frequently mentioned inpatient care as having been part of their treatment. This was in contrast to the other groups, members of which rarely reported having spent time as inpatients.

Participants from all groups expressed negative views of inpatient care: as something

to be avoided if at all possible. Elevated negative symptom group participants rarely spoke about having participated in psychological therapy whereas this was a prominent theme of the Minimal negative symptoms group's accounts. Members of the Minimal and Decreasing groups expressed that they had been able to make choices and exercise control in relation to their treatment. Members of the Elevated group rarely described having been active in deciding the treatment they would receive and sometimes expressed frustration at having control over their life taken away from them during the course of treatment.

Are there differences in the way those who followed differing negative symptom trajectories understood and experienced the process of recovery?

Most members of all groups described themselves as partially, but not fully, recovered. However, their personal understandings of recovery differed. Members of the Elevated and Decreasing groups often set stringent benchmarks for recovery, including both complete remission of symptoms and return to full-time paid employment. These participants mostly felt their own role in their recovery to be limited; some expressed the belief that taking their prescribed medication was the primary means by which they could participate in their recovery.

Members of the Minimal negative symptoms group often deemed reduction in the severity or frequency of symptoms to be sufficient for recovery. Several participants from this group also spoke about part-time or voluntary work – rather than full-time paid work – as being more realistic for them and did not see this concession as being incompatible with recovery. Participants from the Minimal negative symptoms group often described recovery as a matter of learning to cope with ongoing symptoms. They saw their role in the process of recovery as an active, ongoing one: they felt that their recovery was ultimately in their hands: professionals could provide them with the tools but it was up to them to use them.

7.5.2. Interpretation, Relevance to the Literature and Theoretical Significance

As in previous studies of personal explanations of psychosis (J. A. Larsen, 2004; Werbart & Levander, 2005), the two modes of explanation favoured by participants in the current study can be related to the previously discussed contrasting recovery styles – ‘sealing over’ and ‘integration’ – distinguished by McGlashan et al. (1975). The relatively complex psychosocially focused explanations favoured by most members of the Minimal group can be seen as evidence of an integrative recovery strategy. Participants from the Elevated and Decreasing groups who held a biomedical view of their psychosis might be thought of as sealing over their experience: through adopting a biomedical explanation of their unusual experiences, they were able to avoid linking these experiences to other aspects of their life. Interestingly, Thompson et al. (2003) found that a sealing over recovery style predicted poorer functional outcome at 12 months post stabilisation of a first psychotic episode. Thus, it could be hypothesised that a tendency towards a sealing over recovery style may be implicated in the relatively poor social recovery observed in members of the Elevated and Decreasing groups.

However, the biomedical understandings of psychosis expressed by many members of the Elevated and Decreasing groups appeared to have conferred some advantages. One advantage mentioned by participants was that understanding their experiences as being due to an illness absolved them of blame for their problems. Unlike sufferers of physical health problems, those experiencing mental health problems are often held responsible for their illness. The view that those with mental health problems are ‘weak not sick’ has been identified as an important component of mental health stigma (Jorm & Wright, 2008). It has been suggested that such attitudes are the remnants of traditional Christian notions of insanity being a consequence of personal sin (Dain, 1992). Prior to enlightenment rationalism, all forms of misfortune, including physical ill health, were commonly viewed as ‘the wages of sin’. However, as modern science began to offer alternative explanatory models, the idea that physical illnesses could be attributed to personal sin fell out of favour. Making mental health problems akin to physical illness by attributing biological aetiologies

absolves the individual of personal responsibility for their condition since a person cannot be held blameworthy for being ill.

The legitimation of illness offered by the biomedical model of illness is closely related to the concept of the ‘sick role’ (Parsons, 1991). The ‘sick role’ absolves the individual of personal responsibility for their condition since a sick person cannot be expected to get well by an act of will. The sick role also grants exemption from normal social role responsibilities, typically involving withdrawal from work or school and entering into a state of passive dependence. This legitimation of withdrawal might make the sick role particularly attractive to individuals with the most severe negative symptoms. However, it might also serve to maintain negative symptoms since the sick role does not just legitimise withdrawal and passivity but requires it: the sick person is under a social obligation to limit their usual activities, accept medical treatment, and enter into a dependent social role in which they are looked after by others. Failing to meet these obligations may mean the individual is no longer afforded the privileges of the role.

Kvaale et al. (2013) reviewed and undertook meta-analysis of 28 experimental studies that examined the effect of biomedical explanations of psychological problems on stigma. In line with the results of the current study, Kvaale et al. found that biomedical explanations tend to lead to reductions in blaming attributions. However, they also found that these explanations tend to result in greater prognostic pessimism. It should be noted that these findings relate to the stigmatisation of others rather than to self-stigma. However, since those who experience FEP are part of the wider population and influenced by the same cultural milieu as other members of the population, it is possible that these findings also apply to individuals’ attitudes to their own psychological difficulties. Thus it is plausible that while adoption of a biomedical theory of psychosis might serve to alleviate self-blame, it might also induce pessimism regarding the prospect of recovery.

The finding that members of the Minimal negative symptoms group tended to offer relatively complex explanations of the genesis of their psychosis recalls the results of

a quantitative study by Lysaker et al. (2012). The authors explored the relationship between negative symptom severity and personal narrative development in individuals diagnosed with schizophrenia. Participants were prompted to tell the story of their life, and to discuss the role of their mental health problems within this story. Transcripts of the resulting accounts were subsequently rated for the extent to which four key aspects of the narrative were developed. Narrative development was found to be significantly associated with negative symptom severity, with well-developed personal narratives being associated with less severe negative symptoms. The findings of the current study suggest that there may be a similar association between narrative development and negative symptom severity in FEP. Lysaker et al. speculate that their findings might indicate that diminished narrative complexity leads to negative symptoms or vice versa. However, further research is necessary before we can conclude that there is a causal relationship between negative symptoms and personal narrative development.

A plausible explanation of the finding that more members of the Elevated group spoke about having been hospitalised than members of other groups, is that those with persistent negative symptoms are more likely to experience hospitalisation than other FEP patients. Cognitive models of negative symptoms suggest that discouraging life events can precipitate the dysfunctional beliefs proposed to underlie negative symptoms; the experience of hospitalisation might be one such life event. Some participants in the current study expressed that hospitalisation was an unpleasant and demoralising experience. This accords with previous qualitative findings regarding the experience of inpatient care. For instance, Perry et al. (2007) found that participants described feeling trapped, powerless and dehumanised during their inpatient stays. Fear and vulnerability have also been found to be characteristic of patients' experience of psychiatric hospitalisation (Fenton et al., 2014). Thus the experience of hospitalisation might be hypothesised to play a causal role in the aetiology of negative symptoms. While this it is far from the only possible explanation of this study's findings, it is a particularly interesting one and warrants further investigation.

There are a number of plausible explanations for the prominence of psychological interventions within the accounts of members of the Minimal group relative to other negative symptom groups. As previously discussed, it might be that those with greater negative symptom severity are not offered psychological therapy as often as counterparts presenting with fewer negative symptoms. This could be explained by a belief among those referring service-users for psychological interventions that negative symptoms act as a barrier to successful engagement in talking therapies.

Such a belief may not be entirely unfounded. Baseline negative symptom severity was found to be a significant predictor of outcomes in a small non-controlled trial of CBT for auditory hallucinations (Thomas, Rossell, Farhall, Shawyer, & Castle, 2011). However, it is unclear whether this finding can be taken as evidence that negative symptoms act as a barrier to effective utilisation of CBTp. An analysis of data from an RCT of CBTp found that, while negative symptom severity was a significant predictor of change across time, it was not a significant predictor of change in the treatment group relative to the control group (Lincoln, Mehl, Kesting, & Rief, 2011). This suggests that limited improvements following CBTp made by those with elevated negative symptoms might be accounted for by the poorer overall outcomes of those with more severe negative symptoms as opposed to their benefiting less from CBT.

Another possible explanation for the relative prominence of psychological interventions within the treatment accounts of members of the Minimal group is that individuals with more severe negative symptoms were more likely to decline psychological therapy. It is reasonable to assume that those with more severe negative symptoms, particularly those who find expressing themselves or being in the company of other people difficult, might find the prospect of participating in talking therapy less appealing than those who do not have these difficulties. Alternatively, this finding could be explained by a lesser propensity amongst members of the Elevated and Decreasing group to discuss the psychological therapy they received. This could be because these participants less often regarded psychological therapy as an important element of their treatment, perhaps linked to their more often embracing a biomedical model of psychosis.

The high degree of choice and power in relationship to their treatment experienced by the Minimal and Decreasing groups contrasts with the findings of most previous research investigating the experiences of mental health service-users. Instead, the picture painted by previous studies is of limited choice and lack of empowerment, mirroring the experience of the Elevated group in this study. For instance, Laugharne et al. (2012) interviewed people with chronic psychosis (median length of illness 25 years) about their experiences of choice and power within mental health services and found that very few participants felt they had any power over the services they received. Indeed, most had not even considered that their having choice in their treatment might be a possibility.

Studies of EIP service-users have found evidence of a perception of greater involvement in treatment decisions (Harris et al., 2012; Lester et al., 2012; O'Toole et al., 2004), in line with the philosophy of responsive, person-centred care underpinning the EIP service model. The treatment experiences of the Minimal and Decreasing groups thus correspond to both the experiences reported by EIP service-users in previous research and to the aspirations of the EIP service model. This raises the question why the treatment experiences of members of the Elevated negative symptom group did not live up to these aspirations. It might be that members of the Elevated group were less able to exercise control over their treatment as a result of being less expressive and so less able to articulate their preferences. Alternatively, it might be that, because this group were generally more unwell, professionals prioritised symptom control over involving the service-user in treatment decisions.

The understanding of recovery expressed by most participants from the Minimal negative symptoms group – that recovery is an active process of learning to cope – corresponds closely with those of a group of FEP service-users in Hong Kong. Lam et al. (2010) concluded that their participants understood recovery to be ‘learning lessons about priorities in living, envisaging a future where they have a valued role, being respected and respecting others’. This view resonates with modern conceptions of personal recovery (Leamy et al., 2011). The convenience sampling method employed by Lam et al. may well have resulted in a sample with generally low levels

of negative symptoms; this might account for the resemblance between the understandings of recovery articulated by Lam et al.'s sample and the Minimal group in the current study. This attitude to recovery is in line with the integration recovery style which involves accepting the experience of psychosis as part of one's identity.

Lam et al. compared the views of recovery expressed by FEP patients to those expressed by psychiatrists in a similar study (Ng, Pearson, & Chen, 2008). They concluded that FEP patients' ideas of what constitutes recovery tend to be very different to those of psychiatrists. They found that most psychiatrists held a 'narrow' and 'idealistic' view of recovery, emphasising remission of symptoms, medication compliance and return to premorbid functioning. However, the views expressed by psychiatrists in Ng et al.'s study are very much in line with the views of recovery expressed by many members of the Elevated and Decreasing groups in the current study. Given that members of these groups tended to ascribe to a biomedical view of psychosis, it makes sense that their understandings of recovery should mirror those of psychiatrists whose training is rooted in such a biomedical approach. This attitude to recovery can be related to the sealing over recovery style with its emphasis of moving on from the experience of psychosis and returning to one's former life.

The themes found to characterise the accounts of each negative symptom trajectory group can be seen as forming a coherent set. In the case of the Elevated group's themes, if a participant has received care in an inpatient setting, and received medication but not psychological interventions, it would not be surprising were he or she to adopt a biomedical view of his or her difficulties. In turn, this biomedical understanding of his or her psychosis might incline him or her towards viewing recovery as a process contingent on medication in which the patient's role is mostly passive. Holding stringent benchmarks for recovery might also contribute to a less active attitude towards recovery since a participant is less likely to be motivated to actively work towards a goal that is perceived as unachievable. Similarly in the case of the Minimal group's themes, it follows that a participant seen in the community whose treatment included psychological therapy might tend towards a psychosocial understanding of his or her difficulties. Having adopted such a psychosocial stance, the participant might come to view recovery as an active process of learning to cope

with any ongoing difficulties. Having been offered choices over the treatment he or she received is also likely to contribute to the participant considering him or herself to have an active role in his or her recovery.

7.5.3. Limitations

As in the study described in the previous chapter, the use of secondary qualitative data imposed a number of limitations. Specifically, the use of secondary data narrowed the research question that could be answered: only aspects of the experience of psychosis that were addressed in the topic guides could be considered and no insight into participants' own views of the impact of negative symptoms on their experience of psychosis could be gained. In addition, the findings of the study posed many questions that it was not possible to answer given the data available. It might have been possible to address some of these questions had the topic guides for later interviews been updated to address emerging themes; since data collection was completed before my analysis commenced this was not possible. Other questions could not be addressed using qualitative methods and will require investigation in future quantitative work.

Although the retrospective nature of data collection could be viewed as a limitation of the study for the reasons previously outlined (section 6.5.3), the timing of the interviews had several advantages in relation to the current study. Since interviews were mostly conducted after the participants time with EIP had come to an end, participants were able to look back over their whole period of EIP treatment rather than just the initial phases of treatment. The timing of interviews might also have allowed participants to talk more meaningfully about their experience of recovery than had they been interviewed soon after their first episode.

7.6. CONCLUSION

There were notable differences between the lived-experiences of those whose negative symptoms took differing courses during their first 12 months of EIP

treatment. Members of the three trajectory groups compared expressed differing understandings of psychosis, gave different accounts of the treatment they received and the degree of control they felt able to exercise over it, and displayed distinct understandings and experiences of recovery. It is not possible to draw any firm conclusions regarding the generative mechanisms underlying these findings. However, they can contribute to the generation of hypotheses which, if supported, may clarify the factors involved in the development and maintenance of negative symptoms, and help explain their relationship with poor social recovery.

PART FOUR

Discussion

Chapter Eight – General Discussion: Towards a Psychosocial Model of the Relationship between Negative Symptoms and Poor Social Recovery in First-episode Psychosis

8.1. OVERVIEW

This thesis has explored negative symptoms occurring early in the course of psychosis using data from a large observational study of individuals who received care from EIP services in the UK. The research aimed to identify distinct trajectories of negative symptom progression and to explore the lived-experiences of those whose negative symptoms followed these distinct courses, as well as identifying predictors of these trajectories and examining their relationship with early social disability. The mixed methods design of the research carried out provided rich, multifaceted insights into the nature of negative symptoms in FEP. After first summarising the findings of quantitative and qualitative studies conducted in turn, this chapter will turn its focus to the integration of these findings. These integrated findings will be related to the wider literature on negative symptoms, and their theoretical and clinical implications discussed. Finally, the strengths and limitations of the research will be considered and suggestions made regarding directions for future research.

8.2. SUMMARY OF FINDINGS

8.2.1. Quantitative Studies

The studies described in Part Two aimed to explore early heterogeneity in the course of negative symptoms and to investigate the relationship between negative symptom course and social recovery. The first study undertaken, an investigation of the factor structure of the PANSS, produced a five-factor solution with a single negative symptoms factor. The items indicating this negative symptoms factor – ‘blunted affect’, ‘emotional withdrawal’, ‘poor rapport’, ‘passive social withdrawal’, ‘lack of

spontaneity and flow of conversation', 'motor retardation' and 'active social avoidance' – were used to measure negative symptom severity in the remainder of the thesis.

In the next study, longitudinal modelling techniques were used to investigate the degree of heterogeneity in negative symptom progression and to marshal this heterogeneity by identifying groups with similar patterns of change within the cohort. Four latent classes, each with distinct negative symptom trajectories during the first 12 months of EIP service use, were identified. Only a small proportion of the cohort were identified as belonging to a latent class characterised by persistently high levels of negative symptoms throughout the 12 month study period. A slightly larger proportion of the sample were identified as belonging to a class with persistent negative symptoms of lesser severity. The second largest class was characterised by initially high but decreasing negative symptoms, suggesting that many of those with elevated negative symptoms on entry to EIP services will experience remission of these symptoms within 12 months. The largest class identified presented with consistently minimal negative symptoms throughout the study period. This group comprised the majority of the cohort, suggesting that most EIP patients do not present with notable negative symptoms at any point during their first year of treatment.

Membership of the class with the highest levels of persistent negative symptoms was predicted by male gender and family history of non-affective psychosis. Initially high but remitting negative symptoms were predicted by poor premorbid social adjustment during adolescence despite relatively good social adjustment during childhood. Family history of non-affective psychosis and baseline depression were also significant predictors of membership of this group.

In line with previous research linking persistent negative symptoms and poor outcome, those with stably elevated negative symptoms were found to be at increased risk of experiencing stably low social functioning during their first year with EIP than would be expected were negative symptom trajectory and social

recovery independent. Participants with initially elevated but decreasing negative symptoms were also at increased risk of stably low social functioning. These participants were less likely to experience improving social functioning than those whose negative symptoms were consistently minimal, despite the swift remission of their negative symptoms.

Given that much of the concern around negative symptoms centres on their connection with poor functional outcome, this qualifies any optimism that might be generated by the finding that many of those with elevated negative symptoms at baseline will experience a remission of these symptoms soon after entering EIP services. Similarly, whilst those with consistently minimal negative symptoms were more likely to recover socially within 12 months than members of other classes, more than half of this group did not make a good social recovery within this period.

8.2.2. Qualitative Studies

The studies described in Part Three aimed to explore the lived-experiences of members of the negative symptom trajectory classes identified in Part Two. The overarching aim was to better understand the lives of EIP service-users who experienced negative symptoms of varying severity and persistence. It was hoped that the insight gained would provide clues as to the mechanisms that sustain negative symptoms in FEP, and help explain what drives the relationship between elevated negative symptoms on entry to EIP and delayed social recovery. In order to facilitate these aims, comparisons were made between the experiences of participants who were members of different negative symptom trajectory classes. Those with stably high negative symptoms and stably mild negative symptoms were merged into a single 'Elevated' negative symptom group for the purpose of the qualitative studies due to the small number of those with the most severe negative symptoms opting to take part in the qualitative sub-study. Thus, three groups of participants were compared: the 'Elevated' group (members of the High Stable or Mild Stable trajectory classes), the 'Decreasing' group (members of the High Decreasing class), and the 'Minimal' group (members of the Minimal Decreasing class).

Experiences and understandings of negative symptoms themselves were the focus of the first qualitative study. Descriptions of phenomena corresponding to the negative symptoms construct featured in the accounts provided by members of each of the three negative symptom trajectory groups. There were not marked differences in the extent to which descriptions of negative symptoms featured in the accounts given by members of different trajectory groups, or in the content of these descriptions. Some participants described being unable to react to events and other people as they usually would, leading to them feeling separated off from the world around them. This sense of detachment was encapsulated by the simile 'like a zombie', which was used by several participants. A minority of participants described decreased internal experience, i.e. decreased emotion, thought or drive, during their psychosis. Whilst a minority of participants put their negative symptoms down to decreased emotional, cognitive or motivation capacity, most participants explained the negative symptoms they described as related to medication side-effects, lack of confidence or attempts to cope with their difficulties through avoiding challenging or stressful situations.

The second qualitative study explored wider aspects of participants' experiences of FEP, including their understanding of their psychosis, treatment experiences and understandings and experiences of recovery. There appeared to be differences in the ways in which members of the different negative symptom trajectory groups made sense of their experience of psychosis. Elevated and Decreasing group participants preferred primarily biomedical explanations of their experiences, whereas Minimal participants often expressed more complex, primarily psychosocial explanations. Whilst there were many commonalities in the treatment experiences of members of different groups, there were also several interesting differences. Participants from the Elevated negative symptom group frequently mentioned experiences of hospitalisation, whereas members of other groups rarely reported having spent time as inpatients. Similarly, members of the Elevated group rarely described having been active in deciding the treatment they would receive, whereas Minimal and Decreasing group members often expressed that they had been able to exercise a good deal of control in relation to their treatment. Conversely, Elevated participants rarely spoke about having participated in psychological therapy, whereas this was a

prominent theme in the accounts given by members of the Minimal negative symptoms group.

The majority of participants from all three groups described themselves as partially but not fully recovered. However, there appeared to be differences between groups in their members' understandings of what it means to be in recovery from psychosis.

The Elevated and Decreasing groups tended to set stringent benchmarks for recovery, including both complete remission of symptoms and return to full-time paid employment. These participants sometimes felt their role in their recovery to be limited to compliance with medical treatment. Members of the Minimal group often deemed reduction in the severity or frequency of symptoms, and part-time or voluntary work to be sufficient for recovery. The majority of participants from this group viewed their role in the recovery process to be an active, ongoing one, involving learning to cope with any ongoing or recurring symptoms.

The themes from both qualitative studies that characterised the experiences of each negative symptom trajectory group are summarised in Figure 8.1.

Figure 8.1. Themes identified in relation to each research question by negative symptom trajectory group.

Negative Symptoms	Understandings of Psychosis	Treatment	Recovery
Elevated Negative Symptoms	<p>Ongoing alogia?</p>	<p>Just chemical imbalances in your head</p>	<p>Experiences of hospitalisation</p>
Decreasing Negative Symptoms	<p>Like a zombie</p> <p>Medication side-effects</p> <p>A confidence thing</p>	<p>I would like to be able to make the choices which led to my recovery</p>	<p>High benchmarks for recovery</p> <p>Recovery contingent on medication</p>
Minimal Negative Symptoms	<p>Active avoidance</p>	<p>It starts with stress that's in your life</p>	<p>It's a matter of coping</p> <p>Well, actually, I'm in control of this</p>

8.3. INTEGRATION AND THEORETICAL SIGNIFICANCE OF QUANTITATIVE AND QUALITATIVE FINDINGS

Mixed methods research offers the potential to synergise the strengths of quantitative and qualitative methods, providing greater advantages than equivalent discrete quantitative and qualitative studies. However, it is only through integration of the quantitative and qualitative components of a mixed methods investigation that this potential can be realised. As such, the aim of this section is to integrate the quantitative and qualitative findings described in the previous section in the context of the wider negative symptoms literature. Through drawing together these findings a conceptual model of negative symptoms and their relationship with poor social recovery is proposed. This model is intended to generate hypotheses that might be the subject of future empirical investigations.

The quantitative research conducted established that male gender and family history of non-affective psychosis predict negative symptom trajectories characterised by elevated negative symptoms on entry to EIP. These findings might be interpreted as evidence of biological vulnerability to negative symptoms. This interpretation fits with neurodevelopmental models of negative symptoms which propose that negative symptoms are manifestations of an underlying biological pathology. However, such models struggle to explain the swift remission of negative symptoms experienced by many participants; if negative symptoms are the manifestation of neurodevelopmental pathology then they would be expected to remain stably elevated once they emerge. A neurodevelopmental model also struggles to accommodate the superior social adjustment during childhood of those who presented with initially high but decreasing negative symptom severity relative to those with consistently minimal negative symptoms. Such superior adjustment does not support the existence of an underlying neurodevelopmental pathology.

Participants' personal explanations of the negative symptoms they experienced also cast doubts on the claim that negative symptoms are direct manifestations of neurodevelopmental pathology. Instead, participants' accounts support the central

tenant of cognitive models of negative symptoms: that negative symptoms often reflect active coping in the face of difficult psychological and social circumstances. If a cognitive approach to understanding negative symptoms is embraced then a number of potential non-biological explanations of the predictive relationship between family history of non-affective psychosis and negative symptom course become available. As previously discussed (section 4.5.2.2), these include the possibility that having a close relative with non-affective psychosis might increase the risk of experiencing difficult life-events, or of developing maladaptive coping strategies. Although neurocognitive factors were not considered in the current research, it might also be that a family history of non-affective psychosis is associated with neurocognitive impairments. Such neurocognitive impairments might be implicated in negative symptoms via their propensity to result in discouraging life events, as per Beck et al.'s cognitive model.

It is also possible that having a family history of non-affective psychosis might be associated with personality traits that predispose an individual to negative symptoms. The aspect of the qualitative work carried out focusing on participants' identities (Appendix D) found that those who experienced persistently elevated negative symptoms described themselves in strikingly similar ways. Adjectives such as shy, quiet and serious reoccurred across these participants' self-descriptions and participants reported that they would have described themselves similarly even before their FEP. This theme might be taken as indicative of a preponderance of schizoid personality traits in those who present with persistently elevated negative symptoms. This interpretation is supported by evidence that premorbid schizoid personality traits are specifically associated with later negative symptom severity in both schizophrenia (Cannon, Mednick, & Parnas, 1990; Cuesta, Peralta, & Caro, 1999) and FEP (Cuesta, Gil, Artamendi, Serrano, & Peralta, 2002). Further, such personality traits have been found to be more common among unaffected relatives of those with psychosis than in the general population (Shih, Belmonte, & Zandi, 2004), providing support for the theory that there may be a familial vulnerability to schizoid traits.

A number of mechanisms might account for this association between schizoid personality traits and negative symptom severity. It might be that, in line with neurodevelopmental models of negative symptoms, schizoid personality traits are the premorbid manifestation of the neurodevelopmental abnormalities that later manifest as negative symptoms. There is considerable overlap between schizoid personality traits, which include taking limited interest and pleasure in experiences and activities, having few close relationships, a preference for solitary activities and emotional detachment or affective flattening (American Psychiatric Association, 2013), and negative symptoms. The degree of overlap is such that it often difficult to distinguish between these personality traits and emergent negative symptoms (Cuesta et al., 2007). Alternatively, schizoid traits might be linked to negative symptoms more indirectly. For instance, it might be that individuals with these traits are more likely to have discouraging experiences and thus to develop the dysfunctional beliefs and negative expectancies proposed by cognitive models to lie behind negative symptoms. This is in line with Staring et al.'s (2013) suggestion that impairments in behavioural and emotional functioning, as well as in cognition, might lead to the discouraging experiences that contribute to negative expectancies.

The association between schizoid personality traits and negative symptoms might also be relevant to understanding why those who present with persistently elevated negative symptoms are more often male. Schizoid personality disorder is more common in men than in women (Corbitt & Widiger, 1995; Samuels et al., 2002); given that personality disorders and traits lie on a continuum with one another, it is reasonable to assume that gender differences in disorders reflect gender differences in personality traits (Paris, 2004). Thus, the relationship between following a trajectory of stably high negative symptoms and male gender observed in this study might be explained by population level differences in the personality traits of men and women.

The quantitative findings described in this thesis suggest that a swift reduction in negative symptoms during the first 12 months of treatment is not associated with a corresponding improvement in functioning. The findings of the qualitative research suggest a possible explanation of this finding. Those who presented with a negative

symptom course characterised by elevated baseline negative symptoms tended to express a more passive attitude to their recovery than those who negative symptoms were consistently minimal. Participants from groups with more severe negative symptoms often conveyed a sense of having little agency in relation to their recovery, believing their role to be largely limited to complying with medical treatment. Their attitudes contrasted with those of most participants who presented with consistently minimal negative symptoms who spoke about recovery as an active process of learning to cope. As such, it might be that the relationship between negative symptoms and social recovery is, in part, explained by the attitudes towards and beliefs about recovery of those who have experienced more prominent negative symptoms. If this were the case, then it would be possible for negative symptoms to decrease but the beliefs and attitudes associated with them to have an ongoing impact on social recovery.

While it is not clear why negative symptoms should be associated with more passive attitudes to recovery, one possibility already discussed is that the understanding of psychosis an individual holds affects their sense of agency in their recovery. Those with a biomedical view of psychosis might feel that there is not much they can do to assist their recovery beyond taking their medication, whereas those who view psychosis as an experience with a psychosocial cause may believe themselves to be more able to alter the course of their recovery. Thus, the predominantly biomedical understandings of psychosis expressed by those who presented with elevated negative symptoms might account for their relatively passive attitude to recovery. Further, it is plausible that having little control over the treatment you receive, found in the qualitative research to be a common experience of those with elevated negative symptoms, might engender a passive attitude to recovery. Conversely, it might also be that having a passive attitude to recovery makes one less likely to exercise control over one's treatment.

These considerations led to the development of a conceptual model of the relationship between negative symptoms and poor social recovery in FEP. The model integrates both quantitative and qualitative findings from this thesis and posits

possible causal mechanisms on the basis of existing theory as outlined above. The model is depicted graphically in Figure 8.2.

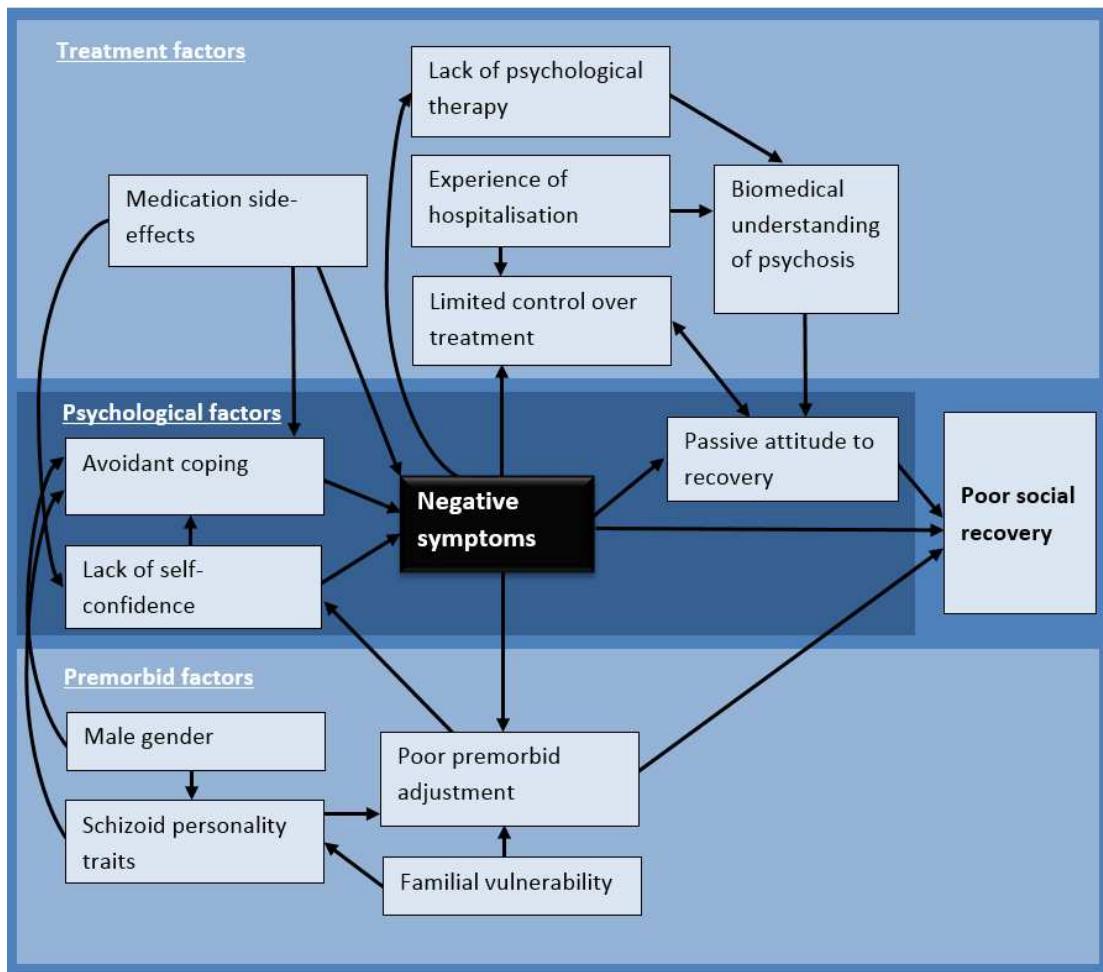


Figure 8.2. Conceptual model of the relationship between negative symptoms and poor social recovery in FEP.

According to this model, avoidant coping strategies, lack of self-confidence and medication side-effects are the most proximal contributors to negative symptoms. Medication side-effects, for instance weight-gain, are also proposed to feed into lack of confidence and avoidance, contributing to negative symptoms indirectly as well as directly. Schizoid personality traits, perhaps related to familial vulnerability and male gender, are proposed to predispose an individual towards avoidant coping strategies, and to lead indirectly to lack of confidence via poor premorbid adjustment. This poor premorbid adjustment is proposed to directly contribute to

poor social recovery: an individual who has struggled to function effectively prior to an episode of psychosis is likely to find it difficult to recover a good level of functioning in its aftermath. However, there is also a hypothesised indirect pathway from poor premorbid adjustment to poor social recovery via negative symptoms.

A passive attitude to recovery, in which the participant sees compliance with medical treatment as their primary role in their recovery, is also hypothesised to contribute to poor social recovery. This passive attitude to recovery is proposed to stem both from negative symptoms themselves and also factors relating to the treatment of FEP patients with elevated negative symptoms, including exercising little control over the treatment they receive, experiences of hospitalisation, and lack of engagement with psychological therapies. Having limited control over treatment decisions is hypothesised to have a direct, bidirectional relationship with passive attitudes to recovery. Experiences of hospitalisation and lack of psychological therapy are proposed to contribute to a passive attitude to recovery indirectly by fostering a biomedical understanding of psychosis.

This model is not intended to be definitive: it is almost certainly flawed and incomplete. Instead, it is intended to generate hypotheses that can be the subject of empirical investigation; the model might then be refined and adapted accordingly. While only concepts that figured in the current research are included in the present version of the model, other factors not featuring in the current research could also be incorporated. For instance, neurocognitive impairment might be included as a premorbid factor that contributes to poor social functioning directly and to negative symptoms indirectly via low confidence and avoidant coping. Wider societal factors could also be incorporated, for instance cultural beliefs about the nature of mental health problems and those who experience them.

8.4. CLINICAL IMPLICATIONS

Negative symptoms are a key area of clinical concern due to their well-established relationship with poor outcomes and the currently limited options for their treatment.

The findings of this thesis suggest that individuals whose negative symptoms follow a trajectory characterised by elevated negative symptoms at baseline, regardless of the path of those symptoms over the next 12 months, are at increased risk of delayed social recovery. As such, a case could be made for providing targeted interventions for those who present with notable negative symptoms on entry to EIP services in an effort to improve rates of social recovery. However, given the poor social recovery of those in the present research whose negative symptoms remitted, it is not clear that successfully reducing negative symptoms would meet the aim of improving social recovery following FEP.

Given that elevated negative symptoms at treatment onset are associated with persistent social disability over the subsequent year whether or not they then remit, it may be that we need to interrupt the formation of negative symptoms before the onset of psychosis in order to have a significant impact on later functioning. This would require intervening at the first signs of non-specific negative symptoms: likely before the emergence of attenuated positive symptoms. Given the likelihood that most individuals identified at such an early stage will never go on to develop psychosis, intervening at this stage might be deemed disproportionate. However, there is evidence that even amongst individuals who do not go on to develop psychosis, prodromal negative symptoms are an important predictor of poor long-term outcomes (Lin et al., 2011). Therefore, if our aim is to prevent suffering and disability regardless of diagnostic categorisation, offering appropriate help at the first signs of emerging negative symptoms may well be justified. This might be achieved by screening young people seeking help from mental health services, and perhaps other at risk groups, for negative symptoms.

The conceptual model set out in the previous section would suggest that the development of psychosocial interventions designed to increase confidence, and reduce the use of avoidant coping strategies through behavioural experiments designed to challenge negative expectancies and increase positive self-concept may be fruitful in reducing early negative symptoms. Social Recovery Cognitive Behavioural Therapy is a new psychological intervention with a strong behavioural focus which aims to improve social functioning through instilling hope and fostering

a more positive self-concept (Fowler et al., 2013; Fowler et al., 2009b). Individuals are encouraged to test their beliefs about increasing activity in behavioural experiments and are supported to engage in activities in line with their values and goals. The intervention is currently being trialled in a group of young people at risk of socially disabling severe mental illness, including those at high risk of psychosis, and has been found to be well accepted by this group (Gee et al., 2016; see Appendix E). If this intervention is successful in improving social functioning in this group, it would be interesting to explore whether the amelioration of negative symptoms has a role in this improvement.

The model proposed suggests that instilling a less passive attitude to recovery may be important to improving social functioning once an individual has experienced their first psychotic episode. Psychological therapies similar to that just described might conceivably be effective in creating a more active stance towards recovery. However, if the conceptual model proposed is correct, the services provided to individuals with persistently elevated negative symptoms must also be considered. Further research is necessary both before we can conclude that there are differences in the services offered and/or utilised by those with persistently elevated negative symptoms relative to those without and before we can be sure of the role of attitudes to recovery in the rate of social recovery following FEP. In the interim, it may be worth encouraging clinicians to be mindful of any differences in the services provided to individuals who present with prominent negative symptoms versus those who do not, and to consider whether any differences are clinically warranted.

Key findings of the current research were presented at a seminar for local clinicians held on 23 May 2016. The seminar was organised in conjunction with a clinical psychologist from CNEIT and was well attended by clinicians from a range of professional backgrounds working with young people experiencing psychotic symptoms. The aim of the seminar was to disseminating the findings of the research in order to maximise its impact locally, and to facilitate the exchange of knowledge and ideas regarding the nature of early negative symptoms and how services can best support young people who experience them. This knowledge exchange process also

enabled feedback on the clinical relevance of the research findings, and potential future directions, to be gathered.

8.5. EVALUATION

8.5.1. Strengths

A key strength of the research described in this thesis is the large, ecologically valid cohort from which its participants were drawn. EDEN is the largest cohort study of UK EIP service-users to be carried out to date and negative symptom data were available at one time point or more for 98% of the cohort. The large sample sizes this facilitated were particularly advantageous for the quantitative research, providing good statistical power and increasing the generalisability of the studies' findings. The large number of participants also allowed for statistical techniques not appropriate for use with smaller sample sizes to be employed. Recruitment rates to EDEN were good – the study succeeded in recruiting 49% of all EIP service-users in the participating regions during the 3.5 year recruitment window – and the available data on non-participating service-users did not suggest any major socio-demographic differences between participants and non-participants (Birchwood et al., 2014) suggesting the cohort was broadly representative of EIP service-users in the UK. No special inclusion criteria beyond the participant being an EIP service-user were imposed and the study was purely observational, minimising selection bias and increasing ecological validity.

The sampling frame for the qualitative studies comprised transcripts of in-depth interviews with 162 EDEN participants, many of whom participated in multiple interviews. Sample size is generally considered to be a less relevant consideration in the evaluation of qualitative research. However, in the case of the qualitative research described in this thesis, the large sampling frame was a distinct advantage. Given the extremely small proportion of High Stable class participants who took part in a qualitative interview (4%), it is likely that a smaller scale study with fewer resources would have failed to capture the views of any such participants. The

relatively large sample sizes afforded by the wealth of available transcripts was also important to fulfilling the comparative aims of the qualitative studies; only by sampling a sufficiently diverse range of participants from each negative symptom trajectory class could meaningful comparisons between groups be made.

Further strengths of the research stem from its mixed methods design. Use of mixed methods allowed a broader range of research questions to be addressed than would have been possible if only either quantitative or qualitative methods had been employed. Further, the use of qualitative methods gave voice to the experiences of individual service-users, avoiding the research becoming divorced from the lived-experience of its participants and countering the somewhat normative approach to understanding negative symptoms and social recovery adopted in the quantitative studies. Integration of the quantitative and qualitative findings prompted the development of a conceptual model of negative symptoms and their relationship with poor social recovery that might be the subject of future empirical investigations.

8.5.2. Limitations

Since major limitations specific to each of the studies described in this thesis have been outlined in their respective chapters, this section will focus on limitations that apply to the research as a whole.

All of the studies outlined in this thesis suffer as a result of the relationship between negative symptom severity and the likelihood of participation (or continued participation) in the research. In the case of the quantitative studies, the greater attrition of members of the cohort with less severe negative symptoms undermined the assumption that data were missing at random, making it almost certain that some bias will have been introduced. In the case of the qualitative research, the small number of participants within the sampling frame who had presented with persistently high levels of negative symptoms resulted in the experiences of only a small number of such participants being included in the analysis.

The reluctance of those who had the most severe negative symptoms to participate in qualitative interviews is hardly surprising. However, the greater loss to follow-up of participants with fewer negative symptoms was entirely unexpected. Indeed, it was anticipated that the reverse may be a problem: that those with more severe negative symptoms might be more likely to decline participation as a result of low motivation and reluctance to meet with an unfamiliar Research Assistant. However, reflection on my personal experience of following-up EDEN participants generated a number of potential explanations of the better retention of those with higher levels of negative symptoms.

First, individuals who had apparently made a good recovery from their psychosis were generally no longer in touch with mental health services, meaning contacting them to invite them to participate was more difficult. Additionally, those who had apparently made a good recovery were often working full-time, and had busy social and family lives. As a result, they were not always willing or able to spare the time to take part in follow-up assessments. In contrast, those participants I met who presented with pronounced negative symptoms were still under the care of mental health services, and often had few daily activities to fill their time. As such, they were generally easily contactable and available to participate in follow-up assessments.

Negative symptoms were treated as a unitary phenomenon for the purpose of this thesis. The coherence of the symptoms identified as negative symptoms in this study was supported by the initial factor analyses. However, it is possible that this might have been an artefact of the methods employed. Given that the negative symptoms construct encompasses a broad range of different behaviours and experiences, a single symptom approach might arguably have yielded more nuanced findings. In particular, given the recent consensus that negative symptoms reflect deficits in two distinct domains (see section 1.4.3), not having distinguished between the expressive and motivational domains is a significant limitation of this thesis. It is possible that these two types of negative symptoms change independently over time, have differing patterns of association with other variables, differ in their relationship to

social recovery, and give rise to quite different lived-experiences. These possibilities may provide fruitful topics of future investigations.

Since the design of the research was purely observational, its findings are unable to justify any causal claims. Members of the latent trajectory classes identified differed in respect to many factors in addition to their negative symptom course. As such, it is quite possible that features found to characterise members of the classes identified were only indirectly related to their negative symptom trajectories. For instance, it is possible that those who presented with stably elevated negative symptoms also presented with more severe psychopathology in other domains. Thus, factors found to predict membership of this class, and the features found to be characteristic of group members' lived-experiences, might be accounted for by their greater overall psychopathology as opposed to their negative symptom course *per se*. More sophisticated study designs will be required to begin to unpick the nature of the relationships observed in the current research.

Whilst the utilisation of pre-existing data was the source of many of the strengths of the work described in this thesis, it also imposed constraints. In an inversion of the standard research process, the research questions were shaped by the data that was available; the measurement of variables, the timing of assessments and the content of topic guides were all fixed prior to the conception of the studies. These constraints resulted in several of the weaknesses described in previous chapters. For instance, as previously discussed (sections 1.4.1 and 3.1), the use of the PANSS to measure negative symptoms has been criticised. Although efforts were made to overcome these limitations to the extent possible, its use to measure negative symptoms remains an important limitation of the research.

A further limitation attributable to the use of secondary data is that some of the data on which this thesis is based were collected as much as a decade ago. The majority of participants received EIP care in the latter half of the 2000s. NHS mental health services have faced significant financial challenges since the turn of the decade, leading to sizeable decreases in EIP service budgets. EIP services experienced a £16

million (26%) reduction in their budget over the course of the 2010 – 2015 parliament, despite an increase in referrals over this period (McNicoll, 2015). In a survey conducted by Rethink Mental Illness in 2014, 58% of EIP teams reported a reduction in staff members in the previous 12 months and 53% said that they believed the quality of the service they were able to provide had deteriorated (Rethink Mental Illness, 2014). The report also highlighted that some regions have merged their EIP services into Community Mental Health Teams in order to reduce costs. As a result, it is likely that the experiences of young people currently experiencing FEP will be somewhat different from the experiences of the participants in the research presented in this thesis. As such, a degree of caution should be exercised in generalising the findings of this thesis to current service-users.

8.6. FUTURE DIRECTIONS

This thesis has focused on the trajectory of overall negative symptom severity over the 12 months immediately following the initiation of EIP treatment. Future research might consider whether patterns of negative symptom change observed during the first 12 months of treatment are sustained in the longer term, and whether they are prognostic of longer-term functioning or other clinically important outcomes.

Exploration of trajectories of change in each of the two negative symptoms subdomains – diminished expression and withdrawal – taken separately would also be a worthwhile endeavour, since it is plausible that one subdomain may be more stable than the other. Relatedly, if it were to prove possible to identify subgroups of FEP patients with distinct profiles of negative symptoms (characterised by either predominant expressive deficits or predominant motivational deficits), it would be interesting to compare the negative symptom trajectories of these subgroups.

Future research should also focus on the course of negative symptoms during the prodromal phase of the disorder and consider the relationship between these earliest trajectories and the course of an individual's negative symptoms following transition to psychosis. Research exploring the nature and course of negative symptoms as they

manifest prior to the onset of frank psychotic symptoms will be of crucial importance in understanding how and why they develop. Considering the relationship between prodromal negative symptom trajectories, concurrent functioning and later social recovery will also be important in understanding the long-term impact of early negative symptoms.

The quantitative research undertaken for this thesis focused on baseline predictors of negative symptom course and as such did not consider the potential influence of treatment on negative symptom course. EIP services offer a range of evidence-based treatments depending on the needs and preferences of individual service-users. As such, members of an FEP cohort are likely to have received a wide variety of interventions, including antipsychotic medications, mood stabilisers and antidepressants, psychological therapies, family interventions, and occupational support. Further, levels of service engagement and medication concordance vary across individuals. Previous research suggests that EIP treatment might have a beneficial impact on negative symptoms (Thorup et al., 2005) but it is not clear which elements of the service are responsible for this. It is possible that differences in treatment contribute to subsequent differences in negative symptoms course. However, as previously discussed, it might also be that the course of an individual's negative symptoms impacts the treatments he or she receives. Research investigating this potentially bi-directional relationship is needed to establish the impact of EIP treatment on negative symptoms and vice versa.

A central component of the model developed to explain the findings of this thesis suggests that the course of an individual's negative symptoms may influence their attitude to recovery and, in turn, their social recovery. However, this theory remains in need of empirical support. Future research should investigate whether beliefs about recovery are relevant to understanding the relationship between negative symptom course and social recovery. There were close parallels between the understandings of psychosis and attitudes to recovery found to be characteristic of those with differing negative symptom courses in the current research and McGlashan's recovery styles. As such, investigating whether there are differences in the recovery styles of those with and without persistent negative symptoms, and

whether any such differences can account for discrepancies in social recovery rates, might be a fruitful line of research. If the hypothesis that the relationship between negative symptom course and social recovery is mediated by attitude to recovery is supported, this would offer hope that social recovery rates following FEP could be improved by intervening to help those presenting with elevated negative symptoms on entry to EIP to develop more adaptive attitudes to recovery.

Ultimately, there is little merit in gaining a better understanding of negative symptoms in FEP if this is not translated into better outcomes for service-users. Therefore, further research seeking to develop and evaluate treatment options for individuals who experience debilitating negative symptoms in the context of early psychosis is vital. It is hoped that the work described in this thesis might be of some assistance to those working to develop interventions with the potential to improve the lives of those who experience negative symptoms.

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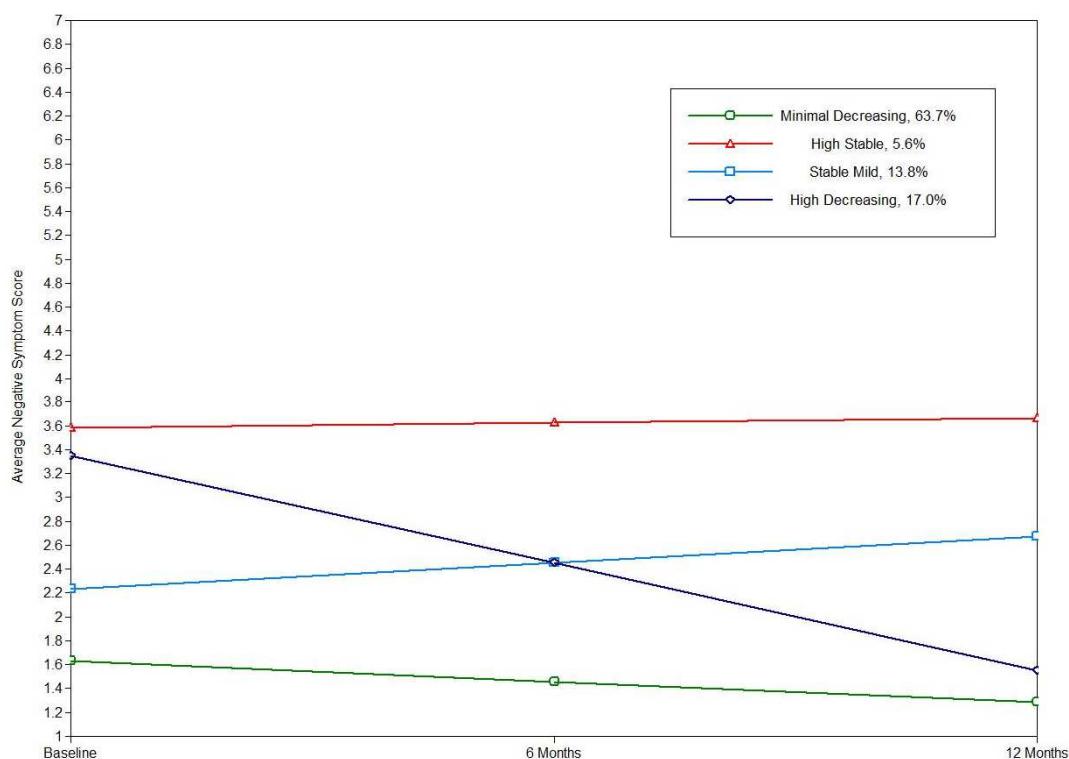
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APPENDICES

APPENDIX A. Supplementary Material

Supplementary Table. Factors and standardised item loadings for EFA six-factor solution, factors 2 and 6 (with identical indicating items to the factors labelled 'Negative' and 'Withdrawn' in van den Oord et al.'s model).

PANSS Items	Factor Loading
<i>Factor 2 – Negative Symptoms (Expression)</i>	
N6 Lack of spontaneity and flow of conversation	0.797
N1 Blunted affect	0.745
N3 Poor rapport	0.697
G7 Motor retardation	0.684
<i>Factor 6 – Negative Symptoms (Withdrawal)</i>	
N4 Passive social withdrawal	0.738
G16 Active social avoidance	0.546
N2 Emotional withdrawal	0.506



Supplementary Figure. LCGA with Four Latent Classes for Participants with Complete Data at Baseline and At Least One Subsequent Time Point: Average Negative Symptom Score Estimated Means.

APPENDIX B. Ethics Documentation

- B1. Letter of ethical approval**
- B2. Participant information sheets**
- B3. Consent and assent forms**

06 May 2005

Dr Helen Lester
Reader in Primary Care
The Medical School
University of Birmingham
Edgbaston
Birmingham B15 2TT

Dear Professor Birchwood and Dr Lester

Full title of study: *A National Evaluation of Early Intervention for Psychosis Services: DUP, Service Engagement and Outcome. (The National Eden Project)*

REC reference number: 05/Q0102/44

The Research Ethics Committee reviewed the above application at the meeting held on 29 April 2005.

Documents reviewed

The documents reviewed at the meeting were:

Document Type:	Version:	Dated:	Date Received:
Application	2	04/04/2005	13/04/2005
Prof. Birchwood's CV		not dated	08/04/2005
Dr Helen Lester's CV		not dated	13/04/2005
Protocol	6	07/04/2005	08/04/2005
Covering Letter		12/04/2005	13/04/2005
Letter from Dr Laverty		04/04/2005	08/04/2005
Letter from Prof. Chilvers		08/04/2005	13/04/2005
Letter from Mrs Hammersley		06/04/2005	08/04/2005
Supplementary Information List		not dated	08/04/2005
Instructions for Completing Consent Forms for Service Users 16+	1	April 2005	08/04/2005
Patient Information Sheet -16+	1	April 2005	08/04/2005
Consent Form-16+	1	April 2005	08/04/2005
Patient Information Sheet -<16	1	April 2005	08/04/2005
Consent Form-<16	1	April 2005	08/04/2005
Patient Assent Form-<16	1	April 2005	08/04/2005

Health Professionals Information Sheet	1	April 2005	08/04/2005
Consent Form- Health Professionals	1	April 2005	08/04/2005
Instructions for Completing Consent Forms for Carers	1	April 2005	08/04/2005
Carer Information Sheet	1	April 2005	08/04/2005
Consent Form- Carer	1	April 2005	08/04/2005
Timetable for data collection	1	April 2005	08/04/2005
Measures collected by table	1	April 2005	08/04/2005
Employment Questionnaire	1	April 2005	08/04/2005
The National Survey of Time Use		not dated	08/04/2005
Personal Details Form	1	April 2005	08/04/2005
Family History Form	1	April 2005	08/04/2005
Duration of Untreated Psychosis	1	April 2005	08/04/2005
Pathways to Care Collated Form	1	April 2005	08/04/2005
Premorbid Adjustment Scale	1	April 2005	08/04/2005
Positive and Negative Syndrome Scale	1	April 2005	08/04/2005
Insight Scale (IS)	1	April 2005	08/04/2005
EQ-5D (Health Questionnaire)		not dated	08/04/2005
Calgary Depression Scale		not dated	08/04/2005
Drug Check		not dated	08/04/2005
The Young Mania Scale		not dated	08/04/2005
Adverse Outcomes Screening Questionnaire	1	April 2005	08/04/2005
Adverse Outcomes Detailed Questionnaire	1	April 2005	08/04/2005
Adverse Outcomes Screening Questionnaire- Carer	1	April 2005	08/04/2005
Global Assessment Of Functioning Scale (GAF), Disability, Symptoms		not dated	
Treatment Documentation Sheet	1	April 2005	
CUTLASS- 7-point Compliance Scale Record		not dated	
Service Engagement Scale		not dated	
Operational Procedure and Criteria for Rating Relapse and Recovery		not dated	
OPCRIT for Windows (v4)		not dated	
Early Intervention Service Fidelity Scale	3	not dated	
Peer Review		not dated	
Semi- Structured Interview Schedule- Users	1	February 2005	08/04/2005
Semi- Structured Interview Schedule- Carers	1	February 2005	08/04/2005
Semi- Structured Interview Schedule- Team Leads and Team Members	1	25/01/2005	08/04/2005

Provisional opinion

The Committee would be content to give a favourable ethical opinion of the research, subject to receiving a complete response to the request for further clarification set out below.

Authority to consider your response and to confirm the Committee's final opinion has been delegated to the Chair.

Further information or clarification required

The Committee would be content to give a favourable ethical opinion of the research, subject to receiving further clarification of the role of the Participant Information Sheet for the under 16s. We would like the heading/title of this to reflect its role for informing relatives/ legal guardians as well as patients about the project in order to obtain both assent as well as consent. We would be grateful if you could submit a Information Sheet with a revised title..

When submitting a response to the Committee, please send revised documentation where appropriate underlining or otherwise highlighting the changes you have made and giving revised version numbers and dates.

The Committee will confirm the final ethical opinion within a maximum of 60 days from the date of initial receipt of the application, excluding the time taken by you to respond fully to the above points. A response should be submitted by no later than 02 September 2005.

"No local investigator" status

The Committee agreed with your declaration that this is a "no local investigator" study. Site-specific assessment is not required for sites involved in the research and no information about the study needs to be submitted to Local Research Ethics Committees. However, you should arrange for the R&D Departments of all relevant NHS care organisations to be notified that the research will be taking place before the research commences.

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Communication with sponsor and care organisation(s)

This communication is confidential but you may wish to forward copies to your sponsor and/or relevant NHS care organisation(s) for their information.

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.

05/Q0102/44

Please quote this number on all correspondence

Yours sincerely,



Dr D M Bailey
Chair

Enclosures

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



PATIENT INFORMATION SHEET
(Over 16 years)

May 2005: Version 2.

Study Title: A National Evaluation of Early Intervention in Psychosis Services: DUP, Service Engagement and Outcome (The National EDEN Project).

You are being invited to take part in a research study. Before you decide whether or not you wish to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

The purpose of the study:

The aim of the project is to evaluate the implementation and impact of Early Intervention Services (EIS) for people aged between 14-35 years of age in different areas of the country.

Why have I been chosen?

We are inviting everyone aged between 14-35 years of age who has been referred to the Early Intervention Service to take part in this study. This will involve approximately 800 young people across the country.

Do I have to take part?

No - involvement in this study is entirely voluntary. However if you decide to take part, you are still free to withdraw at any time without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of health care you receive now or in the future.

What will happen to me if I take part?

If you agree to take part in the study, we will use the data from assessments that have been completed with you by the clinical team. The data will be put into a database and analysed together with data from other clients of the Early Intervention Service (EIS). All data will be anonymised. We would also like to ask you some questions about when you first became unwell, including any incidences of self-harm or violence. This is to determine how you came into contact with the EIS, and also how long you were unwell before contact was made with services.

At this stage we will ask a small number of people (20 in each service, over 2 years) to also take part in a face-to-face interview with a trained researcher who is part of the research team, about their experiences of the Early Intervention Service. The researcher will ask you questions about how easy services are to access, the types of treatments you have been offered, and your general observations on the treatment you have received. The interview will be in a place where you feel comfortable, for example in a quiet room in the Early Intervention Service or in your own home. If you like, you can invite a relative or carer to be present during the interview.

You may also be asked whether you feel that it is appropriate for the research team to contact a friend or relative to ask similar questions. However, this contact will only be made with your permission and the purpose of this contact is to provide them with an opportunity to share their perceptions of how the Early Intervention Service has responded to your needs.

What are the possible side effects of taking part?

Some of the questionnaires **may** cover issues that are sensitive and/or distressing for you – you can stop if you feel uncomfortable at any stage of the interview, and refuse to answer questionnaires that you feel are too distressing.

What are the possible benefits of taking part?

At a national level, since up to 3% of people in the UK develop a serious mental illness, access to good quality mental health services at an early stage of developing an illness may improve an individual's chances of recovery and the quality of life for individuals and their families. On a personal level, involvement in the project may help you think about and reflect more on your treatment and the treatment you would like to receive in future.

What will happen when the research study stops?

This research study lasts for 2 years from July 2005. There will be no change to your care or to services when the study stops, but we hope that the final results of the study will help the health professionals involved in running Early Intervention Services to make changes in the medium to longer term to further improve services. The results of the study will be written up in 2008, you will be able to obtain findings from this project on www.iris-initiative.org.uk and the Rethink website www.rethink.org

Will my taking part in this study be kept confidential?

All information collected as part of this research, including questionnaires, typed up notes of interviews and tape recordings of interviews will be kept in a locked filing cabinet in the Department of Primary Care and General Practice at the University of Birmingham. Any information from or about you will have your name, address and any other identifying features removed, so that you cannot be recognised from it. This means that your anonymity will be preserved at all times during and after the study time period. The tapes will be destroyed 5 years after the study has been completed in line with University of Birmingham research policy.

What will happen to the results of the research study?

The results of the study will be written up for publication in health professional journals and will be presented at conferences in the UK and abroad. However your anonymity will be preserved at all times.

Who is organising and funding the research?

The research is organised by The University of Birmingham, Department of Primary Care and General Practice and funded by a grant from the Department of Health and NIMHE (National Institute for Mental Health in England). Indemnity is provided by the University of Birmingham. The protocol has been reviewed by the Suffolk Local Research Ethics Committee.

Contact for Further Information

Dr Helen Lester, Senior Lecturer in Primary Care, on 0121 414 2684, or Dr Natasha Posner, (National EDEN Project Evaluation Coordinator), on 0121 414 8581, Department of Primary Care and General Practice, University of Birmingham, Edgbaston, Birmingham B15 2TT. If you agree to participate, you will be given a copy of this Patient Information Sheet and a copy the signed consent form to keep.

If you have any concerns about the study and wish to contact someone independent, please telephone Ella Wright, the local ethics committee co-ordinator on 0121 507 5712 between 9am and 5pm.

Thank you for reading this.



PATIENT INFORMATION SHEET

(Under 16 years)

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Will my taking part in this study be kept confidential?

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Thank you for reading this.



THE UNIVERSITY
OF BIRMINGHAM

Centre No:

Patient Identification No for this study:

PATIENT CONSENT FORM

May 2005- Version 2.

Study Title:

A National Evaluation of Early Intervention in Psychosis Services: Dup, Service Engagement and Outcome (The National EDEN Project).

Name of Researcher:

Please initial box

1. I confirm that I have read and understand the information sheet dated May 2005 (version 2) for the above study and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.
3. I understand that sections of any of my medical notes may be looked at by responsible individual from the Early Intervention service, and/or research staff from the University of Birmingham or from regulatory authorities where it is relevant to my taking part in research. I give permission for these individuals to have access to my records.
4. I agree to take part in the above study.

Name of Patient

Date

Signature

Name of Person taking consent
(if different from researcher)

Date

Signature

Researcher

Date

Signature



THE UNIVERSITY
OF BIRMINGHAM

Centre No:

Patient Identification No for this study:

PATIENT ASSENT FORM

May 2005 - Version 2.

Study Title:

A National Evaluation of Early Intervention in Psychosis Services: Dup, Service Engagement and Outcome (The National EDEN Project).

Name of Researcher:

The relative/legal guardian should complete the whole of this sheet himself/herself

Please initial box

1. I confirm that I have read and understand the information sheet dated May 2005 (version 2) for the above study and have had the opportunity to ask questions.
2. I understand that my relative's participation is voluntary and that s/he is free to withdrawal any time, without giving any reason, and without her/his medical care or legal rights being affected.
3. I understand that sections of any of my relative's medical notes may be looked at by responsible individuals from the Early Intervention Service, and/or research staff from the University of Birmingham or from regulatory authorities, where it is relevant to my taking part in research. I give permission for these individuals to have access to my relative's records.
4. I agree to my relative taking part in the above study.

Name of Carer

Date

Signature

Name of Person taking consent
(if different from researcher)

Date

Signature

Researcher

Date

Signature



THE UNIVERSITY
OF BIRMINGHAM

Centre No:

Patient Identification No for this study:

PATIENT CONSENT FORM (Under 16 years)

May 2005- Version 2.

Study Title:

A National Evaluation of Early Intervention in Psychosis Services: Dup, Service Engagement and Outcome (The National EDEN Project).

Name of Researcher:

Please initial box

1. I confirm that I have read and understand the information sheet dated May 2005 (version 2) for the above study and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my medical care or legal rights being affected.
3. I understand that sections of any of my medical notes may be looked at by responsible individuals from the Early Intervention Service, and/or research staff from the University of Birmingham or from regulatory authorities where it is relevant to my taking part in research. I give permission for these individuals to have access to my records.
4. I agree to take part in the above study.

Name of Patient

Date

Signature

Name of Person taking consent
(if different from researcher)

Date

Signature

Researcher

Date

Signature

APPENDIX C. Topic Guides for Qualitative Interviews

- C1. Super EDEN Topic Guide Version 1**
- C2. Super EDEN Topic Guide Version 2**
- C3. Super EDEN Topic Guide Version 3**

Super EDEN Topic Guide Version 1

Topic Guide for Service Users

Sustaining positive engagement and recovery (SuperEDEN) - the next step after early intervention for psychosis

SITE: PARTICIPANT:

Interviewer:

Date:

Build rapport

Be sure to introduce yourself and explain the project

Help the Service User feel at ease

General situation

How have you been feeling recently?

Please can you describe what you do at the moment and where you live (explore activities, income and interests)

Can you describe the things that are most important to you at the moment?

Tell me about your experience with the EIS...

What was the background for you starting in EIS?

When you started, what did you think of the EIS? (Prompt: has your view changed over time? If so, how?)

If you were talking to another person that was about to start with the EIS, what would you tell him/her?

Compared to before you started, has EIS made a difference to you? (Prompt: What you do and how you feel?)

What do you like most about the EIS?

What do you like least about the EIS?

How could the EIS work better for you? (Prompt: what should change, how?)

How long do you think people should spend with EIS?

Super EDEN Topic Guide Version 1

Other services

How does the EIS compare to other types of services you have experienced? (Please also include services for physical health problems)

How often do you see your GP?

In which situations do you see your GP? (Prompt: for which problems and illnesses)

Does your GP support your mental health? (Explore reasons for views)

Support

How does your family view your problem?

What sorts of things do your family help you with?

Who do you feel give you most support?

Is there any kind of support you feel is missing from your life?

Illness perception

How do you understand your problem/what happened to you?

What does this experience mean to you?

Has it influenced how you see yourself and your life?

Relapse plan

If your mental health would get worse, would you know what to do? (Prompt: Do you have a relapse plan?)

Can you describe how the plan was created?

To what extent do you consider yourself active in creating the plan?

Does the plan meet your needs? (Explore answers and thinking behind)

Goals and Recovery

How do you see yourself in the future?

What role do you see mental health playing in your life?

What do you feel you will be doing in 12 months?

Thank you for speaking with me - Is there anything else you would like to say about the EIS that was not covered in these questions?

SUPEREDEN STUDY TWO: *Exploring Service Users' and Caregivers' Lived Experiences of Psychosis and its Treatment through Early Intervention Services*

❖ Interview Information Sheet for Participants: Service Users

In this round of interviews we would particularly like to gain an understanding of the experience of psychosis, and to explore ways in which a person's life, or their sense of who they are, might change during an episode, through recovery, and beyond. We want to listen to what is important to you about psychosis, recovery or treatment and to learn about daily life during these experiences.

With all participants, we would like to briefly explore any issues around **physical health and/or medications** that you may have.

However, there are also four other main interview themes to this part of the study. These are **1) Identity 2) Psychosis 3) Recovery and 4) Family**. From these we would like you to choose which theme or themes you'd like to discuss during the interview today. You could talk about only one or two themes or you could discuss all of them; it's entirely up to you.

Although the interviewer does have a list of possible questions to ask, each question will only be a guide; please feel free to say as much or as little as you like about the theme(s) that you select.

- Theme One: Aspects of Identity**

This theme focuses on exploring how you feel about yourself and whether your identity has changed during the course of psychosis and its treatment.

- Theme Two: Experiences of Psychosis**

This theme aims to find out in more detail what it is like to live through an episode of psychosis. In particular, now that it may be some time since the episode, we'd like to know whether your feelings about, and views on, psychosis have changed at all.

- **Theme Three: Recovery**

The aim of this theme is to gain an understanding of the many things that recovery might mean for different people. It explores what helped you recover, and the kinds of things that happened in life to make you feel that you were beginning to recover.

- **Theme Four: Relationships with Family and Friends**

We would like to know whether you feel that your relationships with your family or friends have changed as a result of your psychosis. And, we would like to understand how people feel about their families, and sometimes friends, being involved in their care.

- **Physical Health and Medications**

This theme explores how you feel about medications that you may have taken for psychosis and also about physical health more generally. It asks whether treatment professionals discuss any side-effects from, or worries about, medications that you may have, and whether how you feel about your body has been changed either by the episode of psychosis or its treatment

Interview Guide: Service Users

❖ For all participants during the interview:

- ***Physical Health and Medications:***

This theme explores how you feel about medications that you may have taken for psychosis and also about physical health more generally. It asks whether treatment professionals discuss any side-effects from, or worries about, medications that you may have, and whether how you feel about your body has been changed either by the episode of psychosis or its treatment

- 1) Has this experience of psychosis also had any impact on your physical health or the way that you feel about your body?
- 2) Do you consider your physical health important?
- 3) Do you ever think, or worry, about your physical health in the future?
- 4) Have your GP or any treatment professionals (eg. EIS, CMHT) ever discussed any aspects of future physical health with you?
- 5) If you have taken medications for your psychosis, how do you feel about these (do they help or hinder)?
 - (If yes to having taken medications): Do you think that the medications that you have taken for psychosis have had any effect on:
 - a) How you feel about your body?
 - b) Your physical health?
- 6) Has a treatment professional ever discussed your medications or possible side-effects with you?
- 7) Do you ever feel that you'd like to discuss aspects of your physical health or medications with a treatment professional?
 - (If yes): Do you have someone with whom you can talk about your medications, any side-effects or worries that you might have?

- ***Transition from Services – At least five minutes at the end:***

- 1) Based on what we have talked about today, how do you feel about leaving Early Intervention Services?

❖ **Possible Interview Questions for the Other Four Main Themes:**

• **Theme One: Aspects of Identity**

1) Describe yourself in a few words.

Are these the same words that you might have used:

- a) Before your episode of psychosis?
- b) During the episode?

2) Has your sense of who you are changed at all since the episode of psychosis?

3) Do you feel, or have you ever felt, that psychosis is part of who you are – of your personality or identity?

4) Have any treatment professionals (such as EIS, CMHT, GP) had an influence on how you view the relationship between psychosis and your identity?

5) Can you describe the most important things in your life at the moment?

6) What are your aims for the future?

- Have these changed at all since the episode of psychosis?

• **Theme Two: Experiences of Psychosis**

1) Describe psychosis in a few words.

Are these the same words that you might have used:

- a) Before your episode of psychosis?
- b) During the episode?

2) Looking back at your episode of psychosis, was there anything positive about this experience?

3) Is there anything about either psychosis or the treatment that have become a part of your life more widely, or of who you are?

4) Have any treatment professionals (such as EIS, CMHT, GP) had an influence on how you understand or view psychosis?

5) Do you feel that you can be, or want to be, honest with treatment professionals about how you are feeling or any symptoms you experience?

6) Have you always felt listened to by professionals that you have been in contact with?

7) Have you ever encountered any issues around confidentiality? (eg. Professionals being unable, legally, to talk to your family even if you would like them to).

- **Theme Three: Recovery**

- 1) Describe recovery in a few words.
Are these the same words that you might have used:
 - a) Before your episode of psychosis?
 - b) During the episode?
- 2) Are recovery and cure the same thing?
- 3) On a day-to-day level, how did you know that you were beginning to recover?
- 4) Is recovery completely desirable or do you ever feel unsure that you want it?
- 5) To recover do you need to accept psychosis, separate yourself from it, or neither/both of these?
- 6) If early intervention services provided support in various forms during your episode – such as talk, medication, activities or other stuff – which, if any, of these do you feel helped you recover?
- 7) Do you have any fears of having another episode of psychosis?
- 8) Have any treatment professionals (such as EIS, CMHT, GP) influenced how you understand or view recovery?

- **Theme Four: Relationships with Family and Friends**

- 1) Have your relationships with family or friends changed since your episode of psychosis?
- 2) Do you think that the psychosis has changed how your friends or family behave towards you?
- 3) Have you ever felt since your episode that you need to behave in a certain way with your family or friends?
- 4) It seems that the involvement of family, and sometimes friends, in a person's care is part of the way that Early Intervention Services care for people. What do you think of this involvement?

SUPEREDEN STUDY TWO: *Exploring Service Users' and Caregivers' Lived Experiences of Psychosis and its treatment through Early Intervention Services*

❖ Interview Information Sheet for Participants: Service Users

In this round of interviews we would like to gain an understanding of your day-to-day experiences of psychosis and recovery, as well as transitions between different healthcare services.

With all participants, we would like to briefly explore experiences of **1) recovery** and, if relevant, also of **discharge from EIS**. However, there are also four other main interview themes to this part of the study. These are **2) Identity; 3) Experiences of Psychosis; 4) Family Life; 5) Physical Health**. From these we would like you to choose which theme or themes you'd like to discuss during the interview today. You could talk about only one or two themes or you could discuss all of them; it's entirely up to you.

Although the interviewer does have a list of possible questions to ask, each question will only be a guide; please feel free to say as much or as little as you like about the theme(s) that you select.

- Theme One: Recovery and Transitions from EIS**

The aim of this theme is to gain an understanding of the many things that recovery might mean to different people. It explores what helped you recover, and the kinds of things that made you feel that you were beginning to recover. If you have been discharged from EIS, we would also like to know what life has been like since leaving the service and to explore your opinions about any other services - such as a CMHT or GP - that you have engaged with.

- Theme Two: Aspects of Identity**

This theme focuses on exploring how you feel about yourself and whether your identity has changed during the course of psychosis and its treatment or through your recovery process.

- **Theme Three: Experiences of Psychosis**

This theme aims to find out what it is like to live through an episode of psychosis. In particular, now that it may be some time since the episode, we'd like to know whether your feelings about, and views of, the illness have changed at all.

- **Theme Four: Relationships with Family and Friends**

We would like to know whether you feel that your relationships with your family or friends have changed as a result of your psychosis. We would also like to understand how people feel about their families being involved in their care and whether family members are supported enough by services.

- **Theme Five: Physical Health and Medications**

This theme explores how you feel about medications that you may have taken for psychosis and also about physical health more generally. It asks if you have experienced any side-effects from your medication and whether any treatment professionals have discussed these side-effects, or any worries that you may have about medications, with you.

Interview Guide: Service Users

- **For all participants during the interview:**

Theme One: Recovery and Transitions from EIS

Part One: Recovery Experiences

- 1) How has life been since we last saw you?
- 2) Are you happy with how your life is going at the moment?
- 3) Do you feel that your life has been changed at all by having gone through your episode?
- 4) Where do you feel that you are in the process of recovery?
- 5) What words would you use to describe recovery?
 - Are these the same words that you might have used:
 - a) Before your episode of psychosis?
 - b) During the episode?
- 6) On a day-to-day level, how did you know that you were beginning to recover?
- 7) Have you experienced any obstacles to your recovery?
- 8) Is recovery completely desirable or do you ever feel unsure that you want it?
- 9) To recover, do you need to accept psychosis, separate yourself from it, or neither/both of these?
- 10) Is your experience of illness something that you'd like to forget?
- 11) Do you see recovery and cure as the same thing?
- 12) Do you have any fears of having another episode of psychosis?
 - (if yes): what is it about this that 'scares' (use word *SU has used*) you?
- 13) Do you feel that you still need the input/support of professionals for your mental health?

Part Two: Recovery and EIS and (if relevant) Other Services

- 1) If EIS provided support in various forms during your episode – such as talk, medication, activities or other stuff – which, if any, of these do you feel helped you recover?
- 2) Did EIS have any influence on how you understood or viewed recovery?
- 3) Did you feel that EIS shared your ideas of what recovery means?
 - (if not:) explore: *Too much/little expectation on behalf of services?*
- 4) How did you feel about leaving EIS?
- 5) How have you felt since leaving EIS?
- 6) Have you missed anything about EIS?
- 7) From EIS where were you discharged to?
 - and, have you been with this service since? (*explore for re-referrals*)
- 8) How did this/these service(s) compare to EIS?
- 9) Have you always felt listened to by professionals in this/these new service(s)?
- 10) Do you feel that this new service shares your idea of what recovery means?
 - (if not:) explore: *Too much/little expectation on behalf of services?*
- 11) Is the way in which the service you are with now talks about psychosis or recovery the same as, or different from, how EIS described these?

- **For all service users not yet discharged from EIS: At least five minutes at the end:**
1) Based on what we have talked about today, how do you feel about leaving Early Intervention Services?

❖ **Possible Interview Questions for the Other Four Main Themes:**

- **Theme Two: Aspects of Identity**
 - 1) What kinds of words would you use to describe yourself?
Are these the same words that you might have used:
 - a) Before your episode of psychosis?
 - b) During the episode?
 - 2) Has your sense of who you are changed at all since the episode of psychosis?
- (if yes:) Are you still changing?
 - 3) Do you feel, or have you ever felt, that psychosis is part of who you are – of your personality or identity?
 - 4) Have any treatment professionals (such as EIS, CMHT, GP) had an influence on how you view the relationship between psychosis and your identity?
 - 5) Have you always felt you could be, or wanted to be, honest with EIS professionals about how you were feeling or any symptoms you experienced?
 - 6) Can you describe the most important things in your life at the moment?
 - 7) What are your aims for the future?
 - Have these changed at all since the episode of psychosis?
 - have these changed over the last year?
 - 8) Is there anything that you'd like to do that you feel your illness experiences may prevent or alter?
 - 9) Is there anything that you'd like to do that you feel your illness experience may help with?

- **Theme Three: Experiences of Psychosis**

- 1) How have you been feeling since we last saw you?
- 2) What words would you use to describe psychosis?
 - Are these the same words that you might have used:
 - a) Before your episode of psychosis?
 - b) During the episode?
- 3) What do you feel may have caused your illness?
- 4) Looking back at your episode of psychosis, was there anything positive about this experience?
- 5) Is there anything about either psychosis or the treatment that have become a part of your life more widely, or of who you are?
- 6) Have any treatment professionals (such as EIS, CMHT, GP) had an influence on how you understand or view psychosis?
- 7) Do you feel that treatment professionals have always shared your idea of what psychosis is?
 - *(if not:) explore these differences – in EIS or later services, or both?*
- 8) Have you ever experienced any prejudice related to your mental health during or since your illness?
- 9) What do you think about how the media talks about mental health?

- **Theme Four: Relationships with Family and Friends**

- 1) Have you always felt able to tell family or friends about your diagnosis?
- 2) Were your family or friends part of what helped you to get through illness and recovery?
 - (*if yes:*) Looking back now, in what ways do you think that your episode may have affected their lives?
- 3) It seems that the involvement of family, and sometimes friends, in a person's care is part of the way that Early Intervention Services care for people. What do you think of this involvement?
- 4) Do you feel that EIS supported your family?
- 5) (*For individuals already discharged from EIS:*) Do you feel that the service(s) that you are with now involve family members in your care as much as EIS did?
- 6) (*For individuals already discharged from EIS:*) Do you feel that the service(s) that you are with now support family members enough?
- 7) Have you ever encountered any issues around confidentiality? (eg. Professionals being unable, legally, to talk to your family even if you would like them to) in any of the services that you have engaged with for your mental health?
- 8) Have any of your relationships with family or friends changed since your episode of psychosis?
- 9) Do you think that the psychosis has changed how your friends or family behave towards you?
- 10) Have you ever felt since your episode that you need to behave in a certain way with your family or friends?
- 11) Do you think that any relationships around you – like those between other members of your family – have changed since your episode of psychosis?
- 12) Since going through the episode and a process of recovery, do you feel that you want to tell new people you meet about having been through psychosis (or not)?

- **Theme Five: Physical Health and Medications**

- 1) If you have taken medications for your psychosis, how do you feel about these (do they help or hinder)?
- 2) If you have taken medications for your psychosis, have you experienced any side effects?
 - (if yes): how do/did you feel about these?
- 3) Has a treatment professional ever discussed your medications or possible side-effects with you?
- 4) Have your GP or any treatment professionals (eg. EIS, CMHT) ever discussed any aspects of future physical health with you?
- 5) If you have taken medications for your psychosis, do you feel that these have had any effect on:
 - a) How you feel about your body?
 - b) Your physical health?
- 6) Do you feel that your illness itself has had any impact on your physical health or the way that you feel about your body?
- 7) Do you consider your physical health important?
- 8) Do you ever think, or worry, about your physical health in the future?
- 9) Do you ever feel that you'd like to discuss aspects of your physical health or medications with a treatment professional?
 - (if yes): Do you have someone with whom you can talk about your medications, any side-effects or worries that you might have?

APPENDIX D: Supplementary Chapter

Identity, Self and Negative Symptoms

1. BACKGROUND AND RATIONALE

Identity comprises the traits and characteristics, social roles, and group memberships that define who an individual is (Oyserman, Elmore, & Smith, 2012). A person's identity provides the content of his or her self-concept: beliefs about who he or she is, has been, and might become. Understanding self and identity has been proposed to be fundamental to making sense of individuals' thoughts, feelings and behaviours (Ashmore & Jussim, 1997). Disruption of identity is a widely recognised consequence of the experience of severe mental health problems (Yanos, Roe, & Lysaker, 2010) and is acknowledged to be an almost universal experience among those diagnosed with schizophrenia (Lysaker & Lysaker, 2002). The experience of schizophrenia has been described as 'an ever-present sense that one's personal identity stands on the brink of collapse, or the experience that such a catastrophe has occurred and only miscellaneous fragments remain' (ibid).

Similar disruption to the sense of self has been reported in individuals experiencing FEP. Research focusing on lived-experiences of FEP has highlighted that individuals often feel disconnected from their former identity, perceiving a loss of their former self and the emergence of a new self-concept (Dunkley, Bates, & Findlay, 2015; Lester et al., 2011; Tan, Gould, Combes, & Lehmann, 2014). Some of these identity changes are perceived as positive; for instance, Hirschfeld et al. (2005) reported that some participants described having grown and developed as a result of their experience of psychosis, gaining maturity, understanding and confidence. However, the majority of studies have found the impact of psychosis on identity to be predominantly negative; loss of occupational roles, changed relationships with others, stigma, negative treatment experiences and changes in physical appearance have all been identified as contributors to profound negative changes in the sense of self of those who have experience of psychosis (McCarthy-Jones, Marriott, Knowles,

Rowse, & Thompson, 2013). Consequently, recovery has been proposed to necessitate either reclaiming one's former identity or working to build a new, more positive identity (Buck et al., 2013).

Lysaker & Lysaker (2004) theorise that the identity disturbance experienced by individuals with psychosis is causally linked to the development and maintenance of negative symptoms. They argue that dialogue, both internal and external, is the foundation of the sense of self, and that disruption of dialogue is what underlies the collapse of identity following psychosis onset. Negative symptoms are hypothesised to have a bidirectional relationship with lack of internal and external dialogical, and thus with identity disturbance. They suggest that a person who experiences reduced emotion and motivation would likely have little to say to themselves or anyone else and, as such, would struggle to maintain a strong sense of self. Equally, lack of a strong, multifaceted identity would incline an individual to withdraw from other people and abandon projects about which they were previously enthusiastic in an attempt to reduce feelings of confusion and failure. They suggest that these processes come together to create a cycle of decline: negative symptoms curtailed dialogue and as this dialogue dwindles, so does one's sense of direction and drive, resulting in further increases in negative symptom severity.

If the theory that negative symptoms both stem from and contribute to a disrupted identity is true, we might expect there to be differences in the way those who experience negative symptoms of differing severity and persistence perceive themselves. The aim of the current study was to investigate whether there were differences in the identities articulated by members of each of the negative symptom trajectory groups described in the body of this thesis. Further, the perceived role of the experience of psychosis in shaping group member's identities was explored.

2. RESEARCH QUESTIONS

1. Are there differences in the way those who followed differing negative symptom trajectories described themselves?
2. Do those who followed differing negative symptom trajectories differ in the impact they believed their experience of psychosis to have had on their identities?

3. METHODS

The method for this study was as outlined in Chapter Six (section 6.3). An identical set of transcripts formed the dataset, and analysis proceeded alongside analyses for the studies reported in Chapters Six and Seven. In order to answer the current study's research questions, sections of the transcripts in which participants described themselves or discussed how their identity had changed over time were the focus of the analysis. Later iterations of the topic guide included the optional theme 'aspects of identity', exploring how participants perceived themselves and whether they felt their identity has changed during the course of their psychosis and its treatment. Sections of interviews during which this theme was explicitly discussed provided much of the data of relevance to the research questions. However, discussions focused on other topics, for instance relationships with family and friends, also contained relevant material.

4. RESULTS

Indicators of introversion

Participants who chose to speak about the 'aspects of identity' theme were asked to begin the discussion by describing themselves in a few words. The set of adjectives chosen by participants from the Elevated negative symptoms group were strikingly

similar to one another; the most commonly recurring words were 'quiet', 'shy' and 'serious'. The following self-descriptions were typical of this group:

R: Can you describe yourself in a few words?

P: Quiet, serious, shy, honest.

Max, Cheshire – Elevated Negative Symptoms

R: So if I ask you to describe yourself in a few words, not always easy, but how would you, what would you, what sort of words would you use or what would you say about yourself?

P: Erm, err, err, quiet, shy and polite probably, yeah.

Daniel, Norfolk – Elevated Negative Symptoms

R: Okay and if you were to describe yourself in a few words, what words would come to mind, how do you see yourself?

P: Shy I suppose, yeah, um, don't know, um, I can't think of anything else.

Nathan, Birmingham – Elevated Negative Symptoms

These self-descriptions would suggest that such participants saw themselves as introverted. It might be hypothesised that these participants had come to think of themselves in this way as a result of having experienced persistently elevated negative symptoms during their psychosis. However, this theory is drawn into question by the observation that most participants who described themselves in this way indicated that they had a similar self-concept prior to the onset of their psychosis. For instance, when asked how a family member would describe him, Tom indicated that he had always been different from other and was something of a loner as a child: that he had few friends and preferred solitary activities.

R: If your, somebody in the family had to describe you, how would they describe you? What words would they use?

P: I don't know, probably if they were to be polite, I don't know, they'd probably say quirky or strange. I'm not - I'm not quiet, but I'm not - I don't know, I'm, much to myself ... I've always been - I've been - I always was quiet as a child, I didn't really have many friends, I was quite quirky and strange, I'd much rather sort of hide away and do my own things, reading and things like that.

Tom, Cambridgeshire – Elevated Negative Symptoms

These traits appeared to have continued into adulthood. He commented later in the interview:

I'm not big on socialising at all, unless - it has to be the right person because I mean I don't like to - if I don't get on with someone 100% I don't see the point in sort of going out, that sort of thing, do you know what I mean?

Tom, Cambridgeshire – Elevated Negative Symptoms

This suggests that, for at least some participants, an earlier tendency towards introversion might have foreshadowed later asocial attitudes and social withdrawal.

Degrees of self-complexity

The ways in which members of the Minimal and Decreasing negative symptom groups chose to describe themselves were highly idiosyncratic; as a result, it was not possible to identify themes in the content of the descriptions given by members of either group. However, there did appear to be differences between groups in the relative richness and complexity of the descriptions given. Members of both the Elevated and Decreasing negative symptoms groups gave relatively thin descriptions of themselves, often offering only a few words and faltering when prompted by the interviewer to elaborate on their descriptions.

R: So how would you describe yourself?

P: Erm, a nice person really.

R: Okay. Good. What else do you think maybe friends and family would say about you?

P: Erm that I'm a very nice person.

R: Okay, would they say anything else?

P: Erm, [inaudible] that would be it.

Steve, Lancashire – Decreasing Negative Symptoms

R: How would you describe yourself?
P: I don't know; same as everybody else.
R: Yeah.
P: Mmm.

Aidan, Norfolk – Decreasing Negative Symptoms

These descriptions contrasted with the comparatively extensive self-descriptions offered by participants from the Minimal negative symptoms group. Whereas members of the Elevated and Decreasing groups tended to focus predominantly on personality traits when describing themselves, members of the Minimal group frequently incorporated family relationships, social roles, and group memberships into their self-descriptions, in addition to personal traits and characteristics.

R: In a few words, how would you describe yourself, what words would you use to describe yourself?
P: Reliable, interesting, erm, relaxed, certain, definite, defined, a character, humble, erm erm erm erm, creator and novelist and, erm erm, a relaxed person who loves to enjoy other people's company as well as their own.

Shelly, Birmingham – Minimal Negative Symptoms

R: Describe yourself in a few words if you can.
P: Pagan, Hindu, Sikh, pro-active, communicator, activist ... I've always been a proactive communicator, I've always been Pagan in my roots, Hindu in my [inaudible] and Sikh in my behaviour ... and then finally I am an activist and that means that I like to actively participate ... whether you're playing tennis, helping old ladies with their shopping, being an active person is about being active.

Alexander, Devon – Minimal Negative Symptoms

R: So I wondered if you could start by saying a little bit about yourself, so describe yourself in a few words.
P: Um, I'm a generally very happy mum of two lovely boys, um, I feel very lucky that I can stay at home and look after my sons and I haven't got to work at the moment, um, and, um, yeah I like to keep busy, I like to do course, like to learn new things, um, um, yeah and pretty much, you know, quite kind of would give anything a try really.

Isabella, Cambridgeshire – Minimal Negative Symptoms

In addition to giving more comprehensive self-descriptions when asked to describe themselves, members of the Minimal group more often laced discussion of their identities into their broader narratives than did members of other trajectory groups. Perhaps as a result of their discussing their self-concepts at greater length, participants from the Minimal group were more likely than members of other groups to discuss potential contradictions between different aspects of their self-concept. For instance, Clara noted a potential contradiction inherent in viewing herself as both confident and anxious.

R: How would you describe yourself now?

P: Kind. Erm, positive sort of kind and caring. Erm anxious, erm but quite proactive.

R: Huh-huh. So does that suggest a little bit more confidence?

P: Hmm, yeah. Yeah, a - yeah. I, I think I would say I've got a lot of confidence for the anxiety that I go through. So it's err.

R: Contra, contradiction.

P: Yeah. That's the word I was going to say. Now, I think I'm a contradiction, complete contradiction.

Clara, Cornwall – Minimal Negative Symptoms

She went on to note several other ways in which she would describe herself as possessing two seemingly opposing traits simultaneously. Similarly, Kelly discussed being both extremely social anxious but also very confident depending on the social role she is inhabiting.

P: When it's just normal chit-chat conversation, I get sort of a bit tongue-tied and stuck on what to say. Where if it's about like what we're doing now, or if it's about work in my job role, I'm fine.

R: Yeah, you've said that before. You said that you feel almost a different person in your job role.

P: Yeah, yeah, I'm fine, I can talk to whoever and it don't bother me. I can go – I've taken – I've escorted people to their hospitals and GP surgeries all on me own, and that doesn't bother me whatsoever. But to be out of that uniform, to be out of my comfort zone, I'm completely different.

Kelly, Norfolk – Minimal Negative Symptoms

Kelly explained that, because the people she is responsible for supporting in her role as a care worker are vulnerable, this pushed her to be a ‘completely different’ version of herself. It appears that this more confident side of her was more than just a front; rather than speaking of pretending not to be anxious whilst at work, she explained that situations in which she would otherwise feel extremely anxious do not bother her ‘whatsoever’ when she is working. Kelly’s account demonstrates the powerful influence of a person’s social role on their identity, and in turn their feelings and behaviour.

‘It’s changed me into a better person’

Participants were asked whether they felt they had changed as a person as a result of their experience of psychosis. Most participants from the Elevated and Decreasing Negative Symptoms groups expressed that they did not feel they had been fundamentally altered by their experience of psychosis. When they did describe having changed in some way, members of these groups most often expressed a belief that their experience of psychosis as having made them a better person in some way, for instance a stronger or more tolerant person.

I’ve experienced things people will never experience, and, in a way, that makes me stronger ... it sounds, it sounds funny, but character building. Erm, it makes you quite resilient, when you’re well, it makes you very resilient.

Hayley, Cornwall – Elevated Negative Symptoms

I’m a stronger person now, yeah. When you have bad or stressful experiences I think over time you, it’s made me, I’m still a sensitive person but I think it’s made me less sensitive because the more bad experiences you have, y’know what I mean?

Max, Cheshire – Elevated Negative Symptoms

It’s kind of made me more tolerant and more aware of other people and that, you know I can look at somebody and say, well maybe they’ve got a bit of a problem or you know maybe they are struggling and I can be a bit more sympathetic. So I think that’s made me more, I don’t know what the word is, not kind but of that ilk.

Stacey, Cornwall – Decreasing Negative Symptoms

Accounts of having become a better person as a result of the experience of psychosis were also found in transcripts of interviews with members of the Minimal negative symptoms group.

'I do a rather poor caricature of myself'

Whilst accounts of having become a better person as a result of the experience of psychosis were a frequent occurrence in the transcripts of all negative symptom groups, the transcripts of interviews with the Minimal group were distinctive in that they also frequently included discussions of the negative impact psychosis had had on their identity. Several participants articulated that they considered themselves to be a somewhat inferior version of their former selves in the wake of their psychosis, or expressed that a part of them had been lost or was missing as a result of their experiences. Such sentiments were expressed particularly poignantly by Ben and by Isabella.

P: And how narcissistic does this sound, but it's really not, I'm still kind of grieving for myself, if that makes sense.

R: Yeah, totally understandable.

P: So do you feel you're a different person then and you're grieving for the person that you were?

R: Yeah.

P: Yeah. And do you think you'll always be a different person? Or do you think that you will in time be back to how you were?

R: Wishful thinking. All I can say is that I think for the past few years when I've been, you know, okay, I do a rather poor caricature of myself.

Ben, Birmingham – Minimal Negative Symptoms

I feel like so much of me has been sucked out from this awful experience, not just the psychosis but what's happened afterwards and the system that I just don't have it in me, I'm kind of a bit, like your soul has been do you know what I mean, it's been, someone's tried to murder it ... it's like that inner child it's a bit like someone's taken it by the neck, strangled it, it's just survived and then shaken it again and then said, right your life's never going to be the same again.

Isabella, Cambridgeshire – Minimal Negative Symptoms

For some participants from the Minimal negative symptoms group, it was involvement with the mental health system and the fact of having been diagnosed with a mental illness, as opposed to the symptoms they experienced, that they felt was responsible for the perceived negative impact on their identity. For instance, Isabella spoke about being 'forced' to incorporate psychosis into her identity as a result of being given a 'label'.

R: You talked about the label of being unwell, how has that influenced you on your view of the relationship between psychosis and your identity?

P: Um, I think it has significantly affected my identity because I always was very much an individual. Yes I compromised to fit in with other people but I was very much a sort of take me or leave me person and I feel this label now has, yeah I'm almost forced to take it on as part of my identity ... I can't, I can't sort of separate myself from it because it's, you know, it's kind of, you know, it's quite a personal to have mental health problem and it's very difficult to just sort of separate it off from yourself.

Isabella, Cambridgeshire – Minimal Negative Symptoms

For other participants, it was the nature of the symptoms they experienced that were detrimental to their identity. In Clara's case, she struggled to reintegrate her identity after holding grandiose beliefs during her psychosis.

R: I mean do you feel that the - that sense of who you are has changed, then, since, since your psychosis? I mean is that what you're saying, that the sense of who you are has changed?

P: Actually, during my psychosis ... I thought I'd been taken over by, by something, so I was living with that for years, and it's only in the recent past that I've sort of, you know, tried to put it to one side and finally I feel a bit more like [Clara] again than whoever the hell I was, or whatever happened. It was - yeah, I haven't married - I haven't got to that point where I can marry it all up as just one process because of everything that's happened. But still very different, very separate things: who I was before, who I was during, who I was after. Completely separate.

Clara, Cornwall – Minimal Negative Symptoms

5. DISCUSSION

5.1. Review of Study Findings in Relation to Research Questions

Are there differences in the way those who followed differing negative symptom trajectories described themselves?

Members of the Elevated negative symptom group gave brief descriptions of themselves focused primarily on aspects of their personality. Members of this group often chose adjectives such as ‘quiet’, ‘shy’ and ‘serious’ to describe themselves, suggesting they would regard themselves as introverted. Members of the Decreasing negative symptom group also tended to give brief descriptions of themselves, often comprised solely of personality traits they would attribute to themselves. No themes related to the content of the Decreasing groups self-descriptions were evident. Likewise, no themes relating to the content of the Minimal negative symptoms group’s self-descriptions were identified. However, the self-descriptions provided by the Minimal group were distinctive in being relatively lengthy and offering a complex, multi-faceted account of their identity, often incorporating family relationships, social roles, and group memberships in addition to personality traits.

Do those who followed differing negative symptom trajectories differ in the impact they believed their experience of psychosis to have had on their identities?

Participants from the Elevated and Decreasing groups often said that they felt psychosis had not impacted their identity in any way. Those from these groups who did report that their experience of psychosis had changed them expressed that it had made them a stronger person or otherwise changed them for the better. Some members of the Minimal negative symptoms group also spoke about psychosis having changed them for the better but several also felt that the experience had been damaging to their identity. For instance, several participants spoke about feeling they were an inferior version of themselves since their experience of psychosis. This

negative change in their identities was attributed to the treatment received for their psychosis as well as to the symptoms they experienced.

5.2. Interpretation, Relevance to the Literature and Theoretical Significance

An early theory dating back to Bleuler (1950/1911) and Kraepelin (1971/1919) linked schizophrenia to a premorbid personality characterised by introversion. It was observed that many of those diagnosed with schizophrenia presented with introverted traits after the onset of the disorder and it was hypothesised that this introversion may be a legacy of premorbid schizoid personality traits (Bellak & Parcell, 1945). Early research failed to confirm a link between introversion in childhood and diagnosis of schizophrenia in adulthood (Offord & Cross, 1969). However, many such studies relied on the researcher's subjective judgments to classify participants as either introverts or extroversion, without reference to clear operationalised criteria or use of validated rating scales (e.g. Bellak & Parcell, 1945; Michael, Morris, & Soroker, 1955). Later work, utilising validated personality measures has provided evidence of an association between Cluster A (schizoid, paranoid and schizotypal) personality traits and psychosis (Dalkin, Murphy, Glazebrook, Mendey, & Harrison, 1994; Keshavan et al., 2005).

Furthermore, there is evidence that premorbid schizoid personality traits may be specifically associated with later negative symptom severity in both schizophrenia (Cannon, Mednick, & Parnas, 1990; Cuesta, Peralta, & Caro, 1999) and FEP (Cuesta, Gil, Artamendi, Serrano, & Peralta, 2002). Schizoid personality traits include preference for solitary activities, limited interest in and enjoyment of experiences and activities, having few close relationships, apparent indifference to the praise or criticism of others, and emotional detachment or affective flattening (DSM-5; American Psychiatric Association, 2013). It has been noted that such personality traits overlap considerably with the deficits categorised as negative symptoms, with the effect that it is near impossible to differentiate between these traits and emerging negative symptoms (Cuesta, Peralta, Gil, & Artamendi, 2007).

This overlap between schizoid traits and negative symptoms makes the task of establishing whether such personality traits impose vulnerability for the development of psychotic disorders or, alternatively, are the early manifestations of disorder, extremely difficult. This task is further complicated by the fact that psychosis typically begins early in the life course, at a time when the personality is still developing. However, evidence that Cluster A personality traits are more common amongst unaffected relatives of those with psychosis than in the general population (Shih, Belmonte, & Zandi, 2004) provides some support for the theory that such traits may reflect an underlying biological vulnerability.

The traits found to be central to the self-descriptions of participants who presented with persistently elevated negative symptoms in the current study – quiet, shy, serious, a loner –whilst they were construed as indicative of introversion during the analysis, might equally be seen as reflecting schizoid personality traits. If this is the case, it would suggest that individuals with elevated negative symptoms not only present with schizoid personality traits, as indicated by previous research, but that these traits are central to their self-concept. The finding that participants from the Elevated negative symptoms group tended to report that they would have described themselves in similar terms before they experienced FEP suggests that these participants experienced a high degree of continuity between their pre- and post-morbid self-concept.

Noting the link between premorbid schizoid traits and negative symptoms, Rector et al. (2005) proposed a continuum theory of negative symptoms. They suggest that the lack of emotional and verbal expression, social withdrawal and reduced motivation that come to be classified as negative symptoms following a psychotic episode represent a continuation, and perhaps exacerbation, of personality traits that might have been classified as schizoid prior to the onset of FEP. Further, they suggest that these characteristics, both as they manifest prior to the onset of psychosis as schizoid personality traits and following psychosis onset as negative symptoms, are rooted in the same negative beliefs and avoidant coping strategies. Whilst the current study is unable to provide firm support for this theory, some participants' accounts align with it. For instance, Tom's belief that it's not worth meeting up with someone who he

doesn't get on with '100%', might be seen as an example of a defeatist performance belief and is of clear relevance to his reported infrequent social contact with those outside his immediate family. His description of his childhood self as having preferred to 'hide away' and 'do [his] own thing', rather than spend time with others would fit with the interpretation that such asocial beliefs post-FEP were an extension of asocial attitudes held prior to the onset of his psychosis.

The Elevated negative symptoms group's apparent lack of self-complexity relative to members of the Minimal group might be taken as support for Lysaker & Lysaker's (2002) theory of the link between negative symptoms and lack of a strong, multifaceted identity. Plausibly, this group's persistent negative symptoms might have served to disrupt internal and external dialogue, thereby depleting the self-concept, in turn decreasing their affect and drive. However, the finding that the identities of those whose negative symptoms remitted early on appeared to be similarly lacking in complexity raises doubts about this explanation. That it was social aspects of identity in particular that were less developed in the accounts of the Elevated and Decreasing groups is notable. The relatively poor early social recovery of members of both these groups provides a possible explanation for this finding. Individuals whose social functioning is impaired are likely to have fewer relationships, social roles and group memberships than those who make a better social recovery. If such relationships, roles and group memberships have fallen away, then the facets from which identity is typically formed are greatly reduced, resulting in a depleted self-concept.

Given that identity disruption has been acknowledged as a universal feature of schizophrenia (Lysaker & Lysaker, 2002), it is interesting that members of the Elevated negative symptoms group in this study often denied that their identity had been impacted by the experience of psychosis. While some members of this group did report that psychosis had changed them for the better in some respects, they did not acknowledge that psychosis might have had any detrimental impact on their identity. In contrast, members of the Minimal group often spoke at some length about the way in which their experience had undermined their sense of self. It is possible that members of the Minimal group experienced the disruption of their lives

by their psychotic episode as more damaging to their identity than participants who were lower functioning prior to psychosis onset. According to the theory of temporal self-appraisals, favourable comparisons of current selves with past selves are important to maintaining a positive self-identity (Wilson & Ross, 2001). However, individuals diagnosed with schizophrenia often engage in upwards comparisons with past selves, particularly more distant past selves (Dinos, Lyons, & Finlay, 2005). It is possible that this maladaptive pattern of self-appraisals might be more pronounced in individuals who were functioning relatively well adapted prior to their psychosis and so experienced a significant drop in their functioning following the onset of their psychosis. Alternatively, it may be that participants from all groups experienced their identity as damaged by their experience of psychosis but only members of the Minimal group were able or willing to articulate this.

5.3. Limitations

In addition to the limitations this study shares with the qualitative studies described in the body of this thesis, there are a number of limitations specific to this study which should also be borne in mind when interpreting its findings.

Since identity is multifaceted and dynamic, the words as person chooses when asked to describe themselves are likely to be time and context dependent. For instance, if asked to describe oneself during a job interview one would likely mention quite different attributes than one might include in a profile for a dating website, but this would not make either description necessarily false. Context influences the social desirability of disclosing certain parts of one's self-concept, as well as altering the relative salience of the various aspects of one's identity. The participants in the current study were asked to describe their identity in the context of an interview about their experiences of mental health services. The impact of this (rather unusual) situation on the self-descriptions offered by participants should not be underestimated.

A further limitation of the study arises from the fact that all interviews were carried out after the participants' experience of FEP. It is inevitable that participants' experiences after psychosis onset will have influenced how they recall their previous sense of self. It is possible, for instance, that members of the Elevated group would have described themselves quite differently before they became unwell; they might only have come to see themselves as having always been quiet and withdrawn in the light of their experience of negative symptoms. This limitation could be addressed by future prospective research exploring the development of the identities of those at high risk of psychosis.

6. CONCLUSION

The findings of this study suggests that certain schizoid traits may be central to the self-concept of those who experience persistently elevated negative symptoms early in their psychosis. Individuals in this study whose negative symptoms followed this trajectory expressed less complex identities, incorporating fewer social roles and group memberships than did those who experienced consistently minimal negative symptoms. This might suggest that the experience of negative symptoms and/or poor social functioning had a detrimental impact on the identities of those who presented with more severe negative symptoms. However, it was participants who experienced minimal negative symptoms who were most likely to describe their identity as having been adversely impacted by their experience of psychosis. Where members of this group acknowledged their identity as having been impacted at all, those who presented with persistently elevated negative symptoms reported that their experience of psychosis had changed them for the better.

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APPENDIX E. Published and Submitted Papers

E1. Gee, B., Hodgekins, J., Fowler, D., Marshall, M., Everard, L., Lester, H., Jones, P. B., Amos, T. Singh, S., Sharma, V., Freemantle, N., Birchwood, M. (2016) The Course of Negative Symptoms in First Episode Psychosis and the Relationship with Social Recovery. *Schizophrenia Research*, 174, 165-71. doi:10.1016/j.schres.2016.04.017

E2. Gee, B., Notley, C., Byrne, R., Clarke, T., Hodgekins, J., French, P., Fowler, D. (2016) Young People's Experiences of Social Recovery Cognitive Behavioural Therapy and Treatment As Usual in the PRODIGY Trial. *Early Intervention in Psychiatry*. doi:10.1111/eip.12381

E3. Gee, B., Hodgekins, J., Lavis, A., Notley, C., Birchwood, M., Everard, L., Freemantle, N., Amos, T., Jones, P. B., Marshall, M., Sharma, V., Singh, S., Smith, J., McCrone, P., Fowler, D. (Submitted) Lived-experiences of negative symptoms in first-episode psychosis: a qualitative secondary analysis.

The Course of Negative Symptom in First Episode Psychosis and the Relationship with Social Recovery

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Abstract

Aims: To investigate trajectories of negative symptoms during the first 12 months of treatment for first episode psychosis (FEP), their predictors and relationship to social recovery.

Method: 1006 participants were followed up for 12 months following acceptance into Early Intervention in Psychosis services. Negative symptom trajectories were modelled using latent class growth analysis (LCGA) and predictors of trajectories examined using multinomial regression. Social recovery trajectories – also modelled using LCGA – of members of each negative symptom trajectory were ascertained and the relationship between negative symptom and social recovery trajectories examined.

Results: Four negative symptom trajectories were identified: Minimal Decreasing (63.9%), Mild Stable (13.5%), High Decreasing (17.1%) and High Stable (5.4%). Male gender and family history of non-affective psychosis predicted stably high negative symptoms. Poor premorbid adolescent adjustment, family history of non-affective psychosis and baseline depression predicted initially high but decreasing negative symptoms. Members of the Mild Stable, High Stable and High Decreasing classes were more likely to experience stably low functioning than the Minimal Decreasing class.

Conclusions: Distinct negative symptom trajectories are evident in FEP. Only a small subgroup present with persistently high levels of negative symptoms. A substantial proportion of FEP patients with elevated negative symptoms at baseline will achieve remission of these symptoms within 12 months. However, elevated negative symptoms at baseline, whether or not they remit, are associated with poor social recovery, suggesting targeted interventions for service users with elevated baseline negative symptoms may help improve functional outcomes.

Key words: negative symptoms/early intervention/functioning/recovery/longitudinal

1. Introduction

Negative symptoms represent a significant unmet clinical need and the search for effective treatments has received renewed interest in recent years (Kirkpatrick et al., 2006). However, the mechanisms that underpin negative symptoms remain poorly understood. Negative symptoms can be subject to significant fluctuations over time, particularly in the early course of psychosis (Edwards et al., 1999; Ventura et al., 2004). Individuals vary in the stability of their negative symptoms (Kelley et al., 2008) and those with persistently elevated negative symptoms are at highest risk of poor outcome (Husted et al., 1992; Mäkinen et al., 2008). Increased understanding of variation in negative symptom course might help illuminate the mechanisms which underlie negative symptoms.

The prevalence of persistent negative symptoms in first episode psychosis (FEP) remains unclear due to the use of inconsistent criteria for persistence. Moreover, grouping individuals into those with persistent negative symptoms and those without might mask the true complexity of individual variation in negative symptom course. Chen et al. (2013) found that variation in negative symptom course in a cohort of schizophrenia patients was best modelled by four distinct trajectory classes, characterised by differing levels of negative symptoms at baseline and a distinctive pattern of longitudinal change. It is not yet known whether multiple negative symptoms trajectories are similarly evident in FEP. This study examines negative symptom trajectories in a large FEP sample using latent class growth analysis (LCGA), a data-driven approach to identifying patterns of longitudinal change within a heterogeneous population. Predictors of the identified trajectories are then investigated.

This study also explores the relationship between negative symptom course and social recovery. Although the association between negative symptoms during FEP and poor functional outcomes is well established (Evensen et al., 2012; Galderisi et al., 2013), the relationship between the trajectory of an individual's negative symptoms and concurrent change in their functioning has yet to be investigated. Understanding the relationship between negative symptom course and contemporaneous changes in functioning might inform the development of targeted interventions to improve functional outcomes following FEP.

2. Method

2.1. Participants

The sample comprises participants in the National EDEN study: a national evaluation of the impact and cost-effectiveness of Early Intervention in Psychosis (EIP) services in the UK (Birchwood et al., 2014). All individuals accepted into EIP services in Birmingham, Bristol, Cambridge, Cornwall, Lancashire and Norfolk between August 2005 and April 2009 were invited to take part. The Policy Implementation Guide (Department of Health, 2001) provides details of the acceptance criteria for these services and the care they offer. In total, 1027 individuals consented to take part: 80% were followed up at 6 months and 77% at 12 months. National EDEN participants assessed with the Positive and Negative Syndrome Scale (PANSS) at one time point or more ($n = 1006$) are included in the current study (see Table 1 for sample characteristics and descriptive statistics).

[Insert Table 1]

2.2. Measures

2.2.1. Positive and Negative Syndrome Scale (PANSS; Kay et al., 1987)

Participants were assessed using the PANSS following acceptance into EIP (baseline) and 6 and 12 months later. The PANSS is a 30-item instrument designed to measure the severity of symptoms associated with schizophrenia. Symptom severity over the previous seven days is

assessed by a trained rater following a semi-structured interview with the participant. Each symptom is rated on a 7-point scale from 1 (absent) to 7 (extreme).

2.2.2. Time Use Survey (TUS; Fowler et al., 2009; Short, 2003)

Time spent in ‘structured activity’ at baseline, 6 and 12 months, as measured by the Time Use Survey (TUS), was used as an index of social recovery. The TUS is a semi-structured interview designed to assess time spent participating in structured activity on average over the previous month. Structured activity is defined as time spent in paid employment, voluntary work, education, childcare, housework, sport and structured leisure activities. The number of hours per week spent engaged in structured activity on average over the previous month was the measure of functioning used to model social recovery trajectories. Social and occupational functioning have been deemed among the most important markers of recovery by experts by both professional (Kane et al., 2003) and lived experience (Pitt et al., 2007). Unlike many measures of functioning employed in psychosis research, the TUS has limited conceptual overlap with negative symptoms, reducing the risk of confounding.

2.2.3. Other Measures Administered at Baseline

Variables hypothesised to be associated with negative symptom course were measured at baseline. Self-reported social and academic adjustment in childhood (up to 11 years) and early adolescence (11 – 15 years) was assessed using the Premorbid Adjustment Scale (PAS; Cannon-Spoor et al., 1982). Duration of untreated psychosis was assessed retrospectively

using the method described by Larsen et al. (1996). DUP was defined as the interval between onset of frank psychosis and commencement of criterion antipsychotic treatment, ascertained using participant report and examination of clinical notes. Continuous data were dichotomised to create a binary DUP variable (long DUP ≥ 9 months) due to the non-linear relationship between DUP and negative symptoms (Boonstra et al., 2012). The Calgary Depression Scale (CDSS; Addington et al., 1994) was used to measure depression and the Drug Check (Kavanagh et al., 1999) to assess illicit substance use. Family history of non-affective psychosis was ascertained through participant report and diagnoses at baseline obtained from clinical notes.

2.3. Analysis Plan

Since it is now accepted that the factor structure of the PANSS is not well represented by the three original subscales (Kay et al., 2000; White et al., 1997), the PANSS items used to measure negative symptoms in this study were determined using Exploratory Structural Equation Modelling (ESEM; Asparouhov and Muthén, 2009). Whilst much work has been carried out to determine the factor structure of the PANSS in schizophrenia samples, fewer studies have examined its factor structure in FEP samples. ESEM is a factor analytic technique which both allows items to load on multiple factors and provides model fit indices, enabling adequate model fit to be verified. This approach was chosen since it has been argued that free estimation of cross-loadings is necessary to adequately reflect clinical reality and thus obtain satisfactory model fit (van der Gaag et al., 2006; van den Oord et al., 2006). ESEM with geomin rotation was conducted and the adequacy of model fit accessed using

three indices. A five-factor model was specified based on the results of exploratory factor analysis.

The study used latent class growth analysis (LCGA; Nagin, 2005) to identify distinct trajectories of change in negative symptom severity. LCGA is a technique used to identify homogenous sub-groups (latent classes) of individuals with distinct patterns of change over time (Andruff et al., 2009). Missing data were estimated using full information maximum likelihood under the assumption that data were missing at random. Models with increasing numbers of latent classes were fitted to the data and the best model selected according to a number of considerations including fit indices, entropy (a measure of the distinctness of classes), accuracy of posterior classifications (probability that participants were assigned to the correct latent class by the model), parsimony and interpretability (Jung and Wickrama, 2008).

Multinomial regression, with latent class according to the selected LCGA model as the dependent variable, was used to examine predictors of negative symptom course. There were twelve candidate exploratory variables: age at psychosis onset; gender; ethnicity; family history of non-affective psychosis; schizophrenia diagnosis; duration of untreated psychosis; premorbid social adjustment in childhood; premorbid social adjustment in adolescence; premorbid academic adjustment in childhood; premorbid academic adjustment in adolescence; baseline depression; and history of substance use. Only variables that differed significantly between latent classes (according to Pearson's Chi-Squared tests and one-way ANOVAs with Bonferroni correction) were entered into the multinomial regression model. An additional, post-hoc one-way ANOVA was conducted to explore whether members of the

identified trajectory classes differed with respect to the severity of expressive deficit versus withdrawal symptoms (as identified through exploratory factor analysis) at baseline.

Trajectories of social recovery were identified by using LCGA to model hours per week in structured activity as measure by the TUS, as described by Hodgekins et al. (2015b). The social recovery trajectory classes of each member of the identified negative symptom trajectory classes were determined by matching the participants in the current study with those included in Hodgekins et al.'s analysis using their identifier code. A matrix of negative symptom versus social recovery trajectories was constructed and individuals assigned to cells of the matrix according to their trajectory permutation. The independence of the trajectories was tested statistically using Pearson's Chi-Squared test and adjusted standardised residuals of the test examined to interpret the results.

Analyses were conducted using SPSS for Windows, Version 22 (IBM Corp., 2013) and Mplus for Windows, Version 7.1 (Muthén & Muthén, 1998-2012).

3. Results

3.1. Exploratory Structural Equation Modelling

A five-factor model which fit the data adequately (RMSEA = 0.054; CFI = 0.914; TLI = 0.874) resulted in a negative symptoms factor including the items 'Blunted affect', 'Lack of

spontaneity', 'Emotional withdrawal', 'Passive social withdrawal', 'Poor rapport', 'Motor retardation' and 'Active social avoidance'. The mean rating of these items was used to measure negative symptom severity. The identified factor structure was similar to that found in van der Gaag et al.'s (2006) study employing similar methods. Mirroring the findings of van de Gaag et al., 'Active social avoidance' was found to load on both the negative symptoms and affective symptoms factors.

3.2. Negative Symptom Trajectories

LCGA models with increasing numbers of latent classes were fitted to the data. Fit indices, entropy, accuracy of posterior classifications, and the size of each class were compared (Table 2) and the four class model selected. The four-class model (Figure 1) fit the data significantly better than the models with one, two or three latent classes according to all fit indices. Further, each of the four latent classes represented a distinct trajectory with theoretical relevance. Mean posterior probabilities were adequate (> 0.70), indicating high probability of classification to the correct latent class and no latent class was made up of less than 5% of the sample. Although the majority of fit indices suggested that the more latent classes included the better model fit, models with five or more latent classes were rejected for reasons of parsimony and interpretability. Models with five or more latent classes included classes comprising a very small proportion of the sample (less than 5%) and these additional trajectories were not sufficiently unique and distinct to add interpretive value.

[Insert Table 2]

[Insert Figure 1]

3.3. Characteristics of Latent Classes

The class size, unstandardised mean intercept, unstandardised mean gradient, the significance of this gradient (and corresponding p-value) for each trajectory class is presented in Table 3.

[Insert Table 3]

3.4. Predictors of Negative Symptom Course

The four negative symptom trajectory classes were compared on demographic and baseline variables. Descriptive statistics for each class are presented in Table 4.

[Insert Table 4]

Class differences were found in gender ($\chi^2 (3) = 9.253$, $p = 0.026$), baseline clinical diagnosis (Fisher's Exact Test, $p = 0.019$), family history of non-affective psychosis (Fisher's Exact Test, $p = 0.001$), premorbid social adjustment in childhood ($F (3, 904) = 5.116$, $p = 0.002$) and early adolescence ($F (3, 864) = 7.240$, $p = <0.001$), premorbid academic adjustment in

childhood ($F(3, 904) = 7.270, p = <0.001$) and early adolescence ($F(3, 899) = 10.236, p = <0.001$), and baseline depression ($F(3, 943) = 11.285, p = <0.001$). These variables were entered into a multinomial regression with negative symptom trajectory class as the dependent variable. The Minimal Decreasing trajectory class served as the reference category.

Compared to individuals in the Minimal Decreasing class, those in the High Stable class were more likely to be male ($B = -1.04, p = 0.03$) and more likely to have a family history of non-affective psychosis ($B = -1.18, p = 0.01$). Compared to the Minimal Decreasing class, those in the High Decreasing class were more likely have a family history of non-affective psychosis ($B = -0.68, p = 0.046$) and had higher levels of depression ($B = 0.09, p = <0.001$). Members of the High Decreasing class also had better premorbid social adjustment during childhood than the Minimal Decreasing Group ($B = -2.21, p = 0.004$) but poorer premorbid social adjustment in adolescence ($B = 2.11, p = 0.003$). Full results of the multinomial regression are available as supplementary material.

3.5. Relationships between Negative Symptom Trajectory and Social Recovery

Three functioning trajectories were identified by Hodgekins et al.: (1) low levels of functioning sustained over the course of the study ('Low Stable'); (2) moderate functioning which increased over the course of the study ('Moderate Increasing'); and (3) initially high functioning which decreased slightly but remained high ('High Decreasing'). The trajectories are depicted graphically in Hodgekins et al. (2015b; figure 1). Both the Moderate Increasing

and High Decreasing classes, but not the Low Stable class, were engaging in levels of structured activity within the non-clinical range by 12 months and were therefore deemed to have made a good social recovery (Hodgekins et al., 2015b). Of the participants in the current study, 759 were also included in Hodgekins et al.'s analysis. These participants were assigned to cells of a matrix according to their permutation of negative symptom versus functioning trajectory (Table 5).

[Insert Table 5]

Negative symptom trajectories and functioning trajectories were not independent of one another ($\chi^2 = 57.06$, $p = <0.001$). Those in the High Stable, Mild Stable and High Decreasing negative symptom classes were over-represented in the Low Stable functioning class, indicating that those who followed a trajectory characterised by elevated negative symptoms at baseline, regardless of whether those negative symptoms decreased, were less likely to recover socially within 12 months. The Minimal Decreasing negative symptoms class were more likely to make a good social recovery within 12 months than members of other classes; nonetheless, the majority (56.9%) fell into the Stable Low functioning class. The proportion of each negative symptom trajectory class that made a good social recovery within the study period is presented graphically in Figure 2.

[Insert Figure 2]

4. Discussion

4.1. General Discussion

This study identified four distinct negative symptom trajectories in a large sample of individuals receiving treatment for FEP. Only a small proportion of the sample (5.4%) had persistently high levels of negative symptoms. A further 13.5% of the sample presented with consistently elevated negative symptoms of lesser severity. The mean intercept of both these trajectories was sufficiently high to indicate multiple clinically significant negative symptoms. Membership of the class with the highest levels of persistent negative symptoms was predicted by male gender and family history of non-affective psychosis. In line with previous research linking persistent negative symptoms and poor outcome, those with stably elevated negative symptoms were over-represented among those with poor social recovery.

A trajectory of initially high but decreasing negative symptoms was followed by 17.1% of the sample. This supports a suggestion in the literature that initially elevated negative symptoms often decrease over time (Savill et al., 2015). Those with remitting negative symptoms were distinguished from those with consistently minimal negative symptoms by poorer premorbid social adjustment during adolescence despite better social adjustment during childhood. They were also more likely to have a family history of non-affective psychosis and had higher baseline depression. Despite the remission of their negative symptoms, this trajectory class were less likely to make a good social recovery than those with minimal negative symptoms at baseline. One possible explanation is that functioning disrupted by negative symptoms

takes time to return to optimal levels following remission of those symptoms, resulting in delayed improvement in functioning relative to negative symptoms. Alternatively, given their poor premorbid adolescent functioning, it might be that the poor social recovery of this group is a legacy of low baseline functioning.

Two subdomains of negative symptoms – expressive deficits and withdrawal (avolition/asociality) – have now been established (Liemburg et al., 2013). Therefore, a question arose whether the relative prominence of the two subdomains differed between trajectory classes. However a post-hoc one-way ANOVA revealed no significant differences between trajectory classes in the proportion of expressive deficit versus withdrawal symptoms at baseline ($F = 2.22$, $p = 0.085$), suggesting negative symptom trajectories were not associated with the type of negative symptoms present at baseline.

The majority of the sample (63.9%) presented with consistently minimal negative symptoms. These participants were more likely to recover socially within 12 months than members of other classes. Nonetheless, more than half of this group did not make a good social recovery; whilst negative symptoms might be an important barrier to social recovery in some individuals, they are by no means necessary for poor social recovery.

4.2. Clinical Implications

The results of this study indicate that a substantial proportion of those with elevated negative symptoms at baseline will achieve remission of these symptoms within 12 months. However, even when negative symptoms remit, they are associated with poor social recovery. As such, those who present with elevated negative symptoms on entry to EIP services might benefit from close monitoring of their functioning and the provision of targeted interventions. Given that those with initially high but decreasing negative symptoms were often functioning poorly prior to psychosis, it is perhaps not surprising that they struggle to recover socially after its onset. Further research focusing on emerging negative symptoms and social disability during the prodromal phase would be helpful in understanding how these difficulties develop. It might be that intervention at this early stage – after the onset of non-specific negative symptoms and early signs of social disability but before the emergence of positive symptoms – is warranted (Fowler et al., 2010). Additionally, it might be that it is beneficial to engage the children of parents with psychosis in interventions designed to prevent early social disability.

4.3. Limitations

Although the PANSS is one of the most widely used measures of negative symptoms severity, it has significant limitations, both in its item content and reliance on behavioural observations for the assessment of experiential deficits (Blanchard et al., 2011). Measures developed since data collection for this study began (e.g. the Clinical Assessment Interview for Negative Symptoms (CAINS; Kring et al., 2013)) have sought to address these

limitations; it would be interesting to compare the results of the current study with those of similar future studies that utilise these recently developed negative symptom measures.

Similarly, whilst the TUS provides a valuable index of social recovery, it is limited in that it measures only quantity of engagement in activity, not quality of engagement or the personal meaning attributed to it. Considering personal recovery – a concept encompassing connectedness, hope, identity, meaning, and empowerment (Leamy et al., 2011) – in addition to functioning in future research could help minimise this limitation.

Complete PANSS data at all three time points were only available for 63.4% of participants.

As previously mentioned, missing data were estimated using full information maximum likelihood under the assumption that data were missing at random (MAR). However, there was evidence that those with lower levels of negative symptoms at baseline were more likely to have missing data: as such, the MAR assumption is not supported. It is arguably preferable for a study of negative symptoms to have higher attrition of participants with lower levels of baseline negative symptoms than vice versa. Nonetheless, since accepting the unsupported assumption that data are MAR introduces bias, the results of the study are in need of replication.

Since participants were assessed at only three time points, the model forms that could be fitted to the data were limited. Further, the follow-up period of the current study was relatively short. Whilst the first 12 months of treatment are an important period for research given EIP services' focus on providing intensive support soon after psychosis onset, it is possible that further trajectories would emerge if participants were followed over a longer period. A longer term follow-up incorporating more frequent assessment would provide a

more nuanced picture of variation in negative symptom course. Since pharmacological treatment and other interventions could be important factors influencing negative symptom trajectories, the impact of treatment variables (including service engagement) on negative symptom trajectories should be explored in future research.

4.4. Conclusions

Distinct negative symptom trajectories can be identified within a FEP cohort. Persistent negative symptoms are observed in only a small proportion; many of those with high levels of negative symptoms at baseline will attain remission of these symptoms within 12 months. However where elevated negative symptoms are present at baseline, whether or not they remit, they are associated with poor social recovery. Further, even those with consistently low levels of negative symptoms mostly do not make a good social recovery following 12 months of EIP.

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Tables:

Table 1. Sample characteristics and descriptive statistics

	Percentage	Mean (SD)	Median (Q ₁ , Q ₃)
Age at Onset	-	20.07 (7.78)	20 (18, 24)
Male Gender	69.1	-	-
Ethnicity			
White British	70.3	-	-
Asian	15.5	-	-
Black	6.8	-	-
Mixed	4.2	-	-
Other	3.3	-	-
Family History of Non-Affective Psychosis	8.9	-	-
Initial Clinical Diagnosis			
Unspecified Psychosis	72.0	-	-
Schizophrenia	10.6	-	-
Bipolar	5.2	-	-
Drug Induced Psychosis	6.7	-	-
Paranoid Psychosis	3.7	-	-
Schizoaffective Disorder	1.7	-	-
Antipsychotic Use at Baseline			
Typical	1.6	-	-
Atypical	78.7	-	-
Both Typical and Atypical	7.9	-	-
No Antipsychotic	12.7	-	-
Antipsychotic Use at 12 Months			
Typical	2.2	-	-
Atypical	76.5	-	-
Both Typical and Atypical	2.3	-	-
No Antipsychotic	18.9	-	-
Baseline PANSS			
Positive Subscale	-	15.28 (6.03)	15 (10, 19)
Negative Subscale	-	14.80 (6.52)	13 (9, 19)
General Subscale	-	32.85 (9.95)	32 (25, 39)
Negative Factor Item Average	-	2.16 (1.00)	1.86 (1.29, 2.86)

PAS Social				
Childhood	-	0.20 (0.21)	0.17 (0, 0.33)	
Adolescence	-	0.23 (0.19)	0.17 (0.06, 0.33)	
PAS Academic				
Childhood	-	0.26 (0.21)	0.25 (0.08, 0.42)	
Adolescence	-	0.36 (0.24)	0.33 (0.17, 0.50)	
Baseline Calgary Depression	-	6.30 (5.38)	5 (2, 10)	

Note. PANSS = Positive and Negative Syndrome Scale; PAS = Premorbid Adjustment Scale

Table 2. Comparison of LCGA models with two to six latent classes

	2	3	4	5	6
AIC	5893.21	5740.96	5639.24	5564.28	5464.70
BIC	5932.52	5795.01	5708.03	5647.81	5562.98
BLRT	0.00	0.00	0.00	0.00	0.00
LMR-LRT	0.00	0.06	0.03	0.13	0.06
Entropy	0.83	0.81	0.79	0.79	0.79
Classification Probabilities	0.96, 0.90	0.84, 0.94,	0.84, 0.92,	0.89, 0.77, 0.91,	0.83, 0.76, 0.91,
Class Size (%)	81, 19	21, 74, 5	14, 64, 5, 17	3, 17, 64, 11, 5	15, 14, 3, 7, 57, 3

Note. AIC = Akaike's Information Criterion, BIC = Bayesian Information Criterion, BLRT = Bootstrap Likelihood Ratio Test, LMR-LRT = Lo–Mendell–Rubin Likelihood Ratio Test. Lower AIC and BIC values indicate superior fit. A significant BLRT or LMR-LRT value is indicative of the model being a better fit than the model with one fewer latent classes. Classification Probabilities = mean posterior probabilities for each class, Class Size = proportion of the sample making up the membership of each class.

Table 3. Characteristics of latent classes

Name	Class size	Unstandardised mean intercept	Unstandardised mean gradient	Significance of gradient
<i>Minimal Decreasing</i>	n = 674 (63.9%)	1.62	-0.17	Sig. (p = <0.001)
<i>Mild Stable</i>	n = 108 (13.5%)	2.19	0.24	Non sig. (p = 0.08)
<i>High Decreasing</i>	n = 174 (17.1%)	3.35	-0.89	Sig. (p = <0.001)
<i>High Stable</i>	n = 50 (5.4%)	3.58	0.05	Non sig. (p = 0.70)

Table 4. Descriptive statistics (mean (SD) unless otherwise indicated) by negative symptom trajectory class.

	Minimal Decreasing (n = 674)	Mild Stable (n = 108)	High Decreasing (n = 174)	High Stable (n = 50)
Age at Onset	19.99 (8.45)	20.65 (5.27)	20.48 (6.54)	18.46 (6.78)
Male Gender	66.9%	77.8%	68.4%	82.0%
White British Ethnicity	70.9%	68.5%	72.4%	58.0%
Family History	6.9%	9.4%	11.5%	25.5%
Schizophrenia Diagnosis	9.8%	10.8%	9.6%	23.4%
DUP \geq 9 months	27.8%	31.8%	28.3%	26.0%
PAS Social - Childhood	0.19 (0.20)	0.25 (0.25)	0.17 (0.19)	0.27 (0.21)
PAS Social - Adolescence	0.21 (0.18)	0.26 (0.23)	0.26 (0.21)	0.31 (0.17)
PAS Academic - Childhood	0.24 (0.21)	0.34 (0.21)	0.26 (0.19)	0.31 (0.21)
PAS Academic - Adolescence	0.33 (0.24)	0.45 (0.24)	0.41 (0.25)	0.41 (0.21)
Calgary Depression	5.61 (5.03)	7.36 (5.62)	8.04 (5.66)	6.86 (6.60)
Substance Use	66.3%	63.2%	68.5%	55.1%

Note. Family History = Family History of Non-Affective Psychosis; DUP = Duration of Untreated Psychosis; PAS = Premorbid Adjustment Scale.

Table 5. Matrix of intersections between negative symptom trajectory classes and social recovery trajectory classes.

		Social Recovery Trajectory Class		
		<i>High Decreasing</i>	<i>Moderate Increasing</i>	<i>Low Stable</i>
Negative Symptom Trajectory Class	<i>Minimal Decreasing</i>	n = 44 (9.0%) Significantly over-represented	n = 166 (34.1%) Significantly over-represented	n = 277 (56.9%) Significantly under-represented
	<i>Mild Stable</i>	n = 4 (4.2%) Within expected range	n = 12 (12.5%) Significantly under-represented	n = 80 (83.3%) Significantly over-represented
	<i>High Decreasing</i>	n = 4 (3.1%) Within expected range	n = 23 (17.6%) Significantly under-represented	n = 104 (79.4%) Significantly over-represented
	<i>High Stable</i>	n = 1 (2.2%) Within expected range	n = 2 (4.4%) Significantly under-represented	n = 42 (93.3%) Significantly over-represented

Note. The text in each cell refers to whether the class is over- or under-represented according to the adjusted standardised residual of the relevant Chi-Squared test.

Figures:

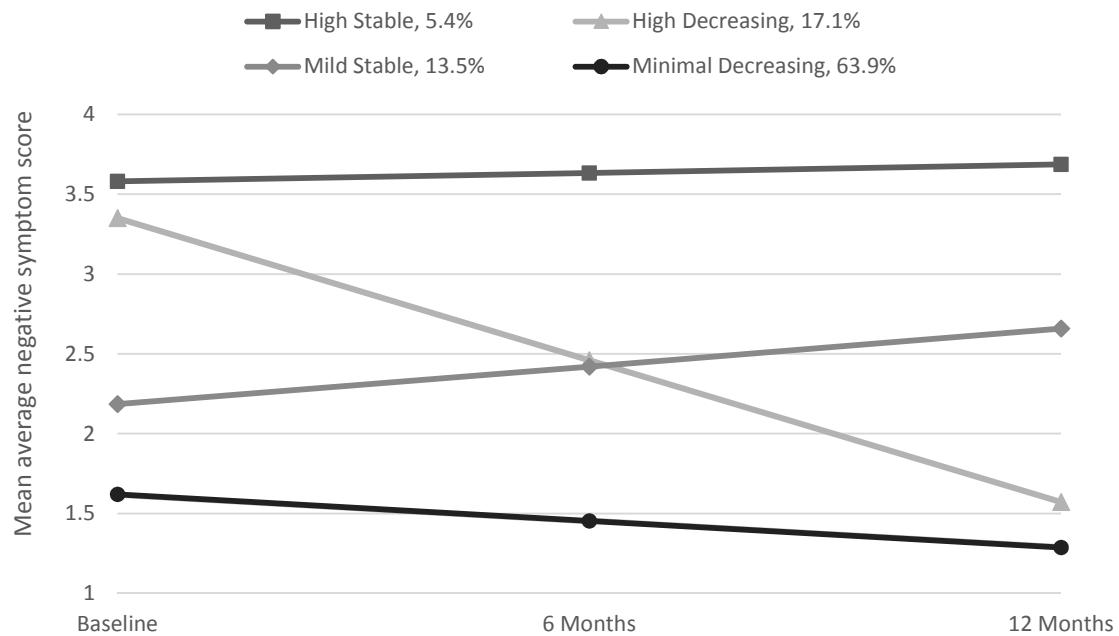


Fig. 1. LCGA with four latent classes: average negative symptom score estimated means

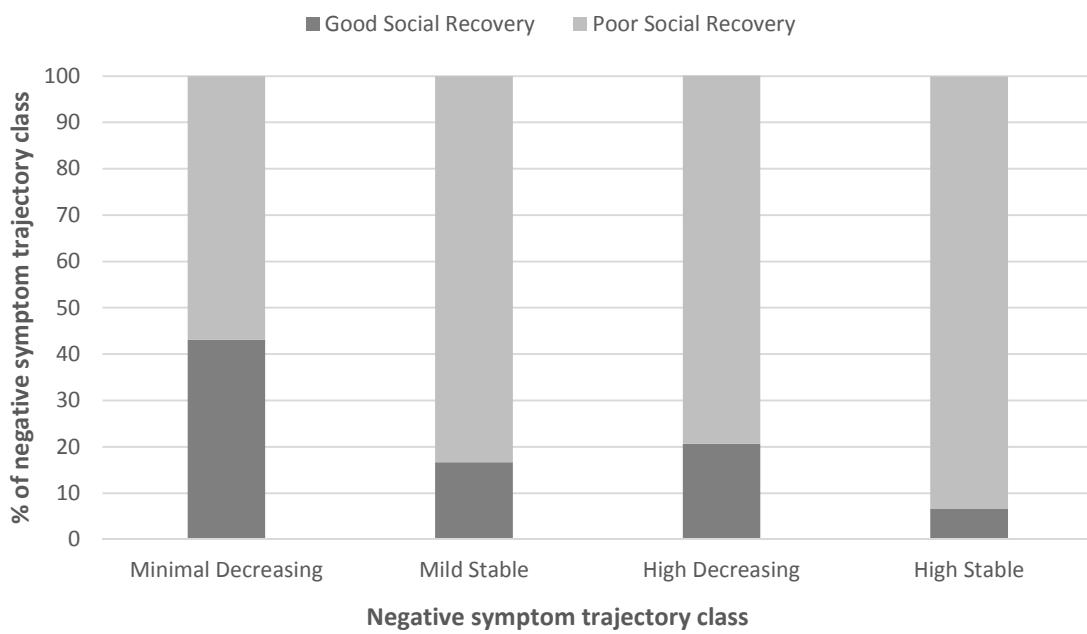


Fig. 2. Proportion of each negative symptoms trajectory class that followed a social recovery trajectory characterised by non-clinical levels of structured activity by 12 months ('Good Social Recovery') versus those with stably low levels of structured activity ('Poor Social Recovery').

Proposed Supplementary Material:

Supplementary Table. Results of multinomial regression investigating predictors of negative symptom trajectories.

	B (SE)	Odds Ratio (95% CI)	P Value
<i>Stable Mild vs. Minimal Decreasing</i>			
Female vs. Male	-0.36 (0.30)	0.70 (0.39 – 1.25)	0.23
Non-Schizophrenia Diagnosis vs. Schizophrenia Diagnosis	0.04 (0.44)	1.04 (0.44 – 2.45)	0.94
No Family History vs. Family History	0.24 (0.48)	1.27 (0.50 – 3.21)	0.62
PAS Social - Childhood	-0.03 (0.84)	0.98 (0.19 – 5.02)	0.98
PAS Social - Adolescence	0.63 (0.84)	1.87 (0.36 – 9.65)	0.46
PAS Academic - Childhood	1.70 (0.90)	5.50 (0.94 – 32.14)	0.06
PAS Academic - Adolescence	0.52 (0.76)	1.68 (0.38 – 7.48)	0.49
Calgary Depression	0.02 (0.02)	1.02 (0.98 – 1.07)	0.35
<i>Stable High vs. Minimal Decreasing</i>			
Female vs. Male	-1.04 (0.48)	0.35 (0.14 – 0.90)	0.03
Non-Schizophrenia Diagnosis vs. Schizophrenia Diagnosis	-0.86 (0.44)	0.42 (0.18 – 1.00)	0.05
No Family History vs. Family History	-1.18 (0.44)	0.31 (0.13 – 0.72)	0.01
PAS Social - Childhood	-0.12 (1.18)	0.89 (0.09 – 8.95)	0.92
PAS Social - Adolescence	2.17 (1.12)	8.79 (0.99 – 78.11)	0.051
PAS Academic - Childhood	0.79 (1.25)	2.21 (0.19 – 25.74)	0.53
PAS Academic - Adolescence	-0.07 (1.08)	0.93 (0.11 – 7.66)	0.95
Calgary Depression	0.05 (0.03)	1.06 (0.99 – 1.12)	0.09
<i>High Decreasing vs. Minimal Decreasing</i>			
Female vs. Male	-0.06 (0.24)	0.94 (0.60 – 1.50)	0.81

Non-Schizophrenia Diagnosis vs. Schizophrenia Diagnosis	0.37 (0.40)	1.45 (0.66 – 3.19)	0.35
No Family History vs. Family History	-0.68 (0.34)	0.51 (0.30 – 0.99)	0.046
PAS Social - Childhood	-2.21 (0.76)	0.11 (0.03 – 0.49)	0.004
PAS Social - Adolescence	2.11 (0.71)	8.26 (2.07 – 33.01)	0.003
PAS Academic - Childhood	-0.26 (0.77)	0.77 (0.16 – 3.67)	0.74
PAS Academic - Adolescence	1.01 (0.62)	2.75 (0.82 – 9.29)	0.10
Calgary Depression	0.09 (0.02)	1.09 (1.05 – 1.14)	<0.001

Note. Model: $\chi^2 (24) = 92.50$, p <0.001. Family History = family history of non-affective psychosis; PAS = Premorbid Adjustment Scale

**Young People's Experiences of Social Recovery Cognitive Behavioural Therapy and
Treatment as Usual in the PRODIGY Trial**

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Abstract

Aim: The PRODIGY trial is an ongoing randomised controlled trial of Social Recovery

Cognitive Behavioural Therapy (SRCBT), a new intervention designed to improve social functioning in young people at risk of long-term social disability due to severe and complex mental health problems. The aim of this qualitative sub-study was to understand trial participants' experiences of SRCBT and the control condition, treatment as usual (TAU).

Method: Trial participants were aged 16 – 25 with socially disabling severe and complex mental health problems. A purposive sample of trial participants took part in in-depth qualitative interviews which were transcribed verbatim and analysed thematically.

Results: Participants from the SRCBT arm valued the relationship with their therapist, the flexibility of intervention delivery and the cognitive and behavioural techniques taught. They viewed SRCBT as challenging but worthwhile. Participants from the TAU arm reported receiving little support, both prior to and during their participation in the trial. Participants from both arms valued opportunities to talk about their difficulties during trial participation. Increased activity was an important goal of participants from both arms and most expressed high motivation and little hopelessness.

Conclusions: Currently available services do not meet the needs of some young people with socially disabling mental health problems. Motivation to change appears high at this early stage of disorder, supporting the potential value of intervening early to prevent longer-term social disability. SRCBT was well accepted by participants and so is a promising intervention to meet this objective.

Key words: Cognitive Behavioural Therapy; Rehabilitation; Youth; Qualitative Research

INTRODUCTION

Three quarters of severe mental health problems are evident before 25 years of age^{1,2}. Such disorder comes at high personal, social and economic cost, much of which is attributable to associated social disability³. However, the needs of young people with severe and complex mental health problems remain largely unmet^{4,5}.

This paper presents a qualitative sub-study of the PRODIGY trial (Prevention of long term social disability amongst young people with emerging psychological difficulties, ISRCTN47998710, UKCRN registration number: 13341). PRODIGY is a multi-site randomised controlled trial (RCT) testing the clinical and cost-effectiveness of Social Recovery Cognitive Behavioural Therapy (SRCBT) in young people with severe and complex non-psychotic mental health problems accompanied by social disability.

SRCBT is designed to improve social functioning in young people at risk of long-term social disability⁶. Barriers to engagement in activity are formulated using a cognitive behavioural therapy approach. The intervention has a strong behavioural focus: individuals are encouraged to test their beliefs about increasing activity in behavioural experiments and therapists liaise with external agencies to support clients to find opportunities to engage in

valued activities. Emphasis is given to understanding individuals' values and goals, and instilling hope.

The use of qualitative methods alongside the PRODIGY trial is an important element of our approach to evaluation. Whilst RCTs are the most rigorous way to evaluate intervention effectiveness, qualitative methods can provide insights crucial to the successful implementation of complex interventions⁷. The current study focused particularly on experiences of SRCBT, aiming to assess acceptability and implementation from participants' perspectives, but also explored experiences of the control condition, treatment as usual (TAU). This was deemed important since little is currently known about what support is accessed, and how this support is experienced, by socially disabled young people, and thus what constitutes TAU for this population.

METHOD

Eligible trial participants were: (a) aged 16–25 years, (b) had severe and complex mental health problems, defined as either meeting 'At Risk Mental State' criteria according to the CAARMS⁸ or scoring ≤50 on the Global Assessment of Function Scale⁹, and (c) spending less than 30 hours per week in structured activity (assessed by the Time Use Survey^{10,11}). Exclusion criteria were psychosis, severe learning disability, organic disorder, and insufficient English language proficiency.

Following ethical approval from the Norfolk Research Ethics Committee, a purposive sample of participants from the RCT's internal pilot who gave consent to be contacted regarding the qualitative sub-study was selected. The aim was to ensure approximately equal representation in terms of gender, study site, randomisation arm, and baseline 'At Risk Mental State'. Further, we sought to recruit participants of a range of ages, with varied previous service-use, and to include looked-after children and the most socially disabled.

After obtaining written informed consent, face-to-face in-depth semi-structured interviews were conducted (by BG in Norfolk and RB in Manchester) either in participants' own homes or a community venue, according to participant preference. Flexible interview schedules focused on history of psychological difficulties, previous experiences of accessing services, experience of trial participation, views on the intervention received, perceived outcomes, and future psychological wellbeing. Interviewers attempted to elicit detailed accounts of treatment experiences and probed for negative as well as positive views. Interviews were audio recorded and transcribed verbatim.

An inductive thematic analysis was undertaken^{12,13}. Data analysis proceeded alongside data collection so that the developing analysis could inform subsequent interviews. We took a critical realist epistemological stance, seeking to understand participants' realities through engagement with their individual perspectives. Analysis involved repeated reading of all transcripts and line-by-line thematic coding, drawing on participants' own words rather than an a priori analytic framework. Each transcript was independently coded by at least two

analysis team members (BG, CN, RB and TC). Where there were discrepancies these were discussed and further analysis undertaken to achieve consensus.

RESULTS

Nineteen young people consented to participate. Of those invited to take part, none declined participation. Unfortunately, one of the nineteen participants did not engage with the interview and a second participant withdrew consent for audio-recording: as such, the final sample comprised seventeen participants (see Table 1 for demographic and clinical characteristics). Three participants had taken part in an earlier qualitative sub-study focusing on experiences of recruitment and randomisation¹⁴. Interviews typically lasted around 60 minutes.

[Insert Table 1]

Thematic analysis revealed four themes specific to the SRCBT arm, three specific to TAU, and three themes spanning the experiences of both arms (Table 2).

[Insert Table 2]

Experiences of SRCBT

'She understood me on a personal level': the therapeutic relationship

The therapeutic relationship was central to participants' experiences of the intervention.

Participants consistently commented on the positive personal qualities of trial therapists, and described the relationship that developed as friendly, informal and genuine, whilst remaining professional and bounded.

I believe she understood me on a personal level as well obviously we didn't go it wasn't any it wasn't unprofessional at all but we spoke about sort of things in general rather than just straight to the therapy it wasn't as clinical as I can imagine some of these services can be with certain people (Liam)

A good rapport appeared to have developed between participants and therapists: participants reported feeling able to talk openly and feeling understood. The way participants spoke about their relationship with their therapist suggested a dynamic of teamwork: participant and therapist working together towards a shared goal, sometimes in partnership with others.

it wasn't like I was being talked at, all my problems were being dissected in front of me without my sort of input, it was a conversation ... it wasn't sort of like someone was talking about the problems they thought I had, it was we were finding out what problems I had and then sorting them out together (Matthew)

Several participants articulated that this strong therapeutic relationship facilitated their continued engagement when the intervention was experienced as challenging. However, for a minority, the closeness of the relationship contributed to difficulties ending therapy.

he was really dedicated to helping me I think he liked me you know and I really liked him so I really found a friend in him um which was really nice really, which has made it even more difficult that you know we had to finish (Harry)

Flexibility

Participants appreciated the flexible way in which the intervention was delivered. They described being offered a choice of locations for sessions and expressed that this helped them to feel comfortable attending and engaging with the intervention.

I just feel comfortable in college and it's good that they can do it here cos if I couldn't do it here I wouldn't do it...I wouldn't have done it otherwise (Abigail)

Some participants also commented that the frequency of sessions was tailored to their individual needs and circumstances.

we continued meeting weekly cos I think in the end ... we both agreed that it was a better idea cos obviously things were so manic and obviously in a hostel things would go from really really good to boff really really bad, so it was, yes, we both agreed that it was a really good idea to do it every week because then we could keep it up

(Katie)

'It's given me tools': the CBT toolkit

Participants spoke about the intervention having equipped them with cognitive and behavioural strategies for managing distress and increasing activity. The most commonly described behavioural strategies were behavioural experiments and activity scheduling. The most commonly described cognitive strategies involved identifying and challenging negative thoughts. A range of other techniques specific to participants' personal difficulties were also mentioned. Participants described practicing these strategies with their therapists during sessions and most reported that they continued using these strategies independently after the intervention. Several participants believed that continued use of the strategies learnt during SRCBT contributed to continuing improvement after the intervention's conclusion.

I've improved so much and it's given me a lot of things that I can continue to improve on ... there's always going to be things that make me nervous so there's always going to be things that I'm going to want to push myself to do if that makes sense so I wouldn't say I'm over it but I've improved so much and it's given me the building blocks to continue to improve (Matthew)

However, one participant felt strongly that he was not ready to employ the strategies he had learnt independently and that gains from the intervention were not fully maintained as a result. He felt the intervention would need to have been longer for him to have felt confident using the techniques independently.

I was worried that things would go sour after [the intervention ended] and it turns out that they didn't stay quite as good after he left ... I didn't haven't take quite long enough to really absorb [the techniques] (Harry)

No pain, no gain: SRCBT as difficult

Whilst participants generally expressed positive views of SRCBT, they were clear that engaging with the intervention was not easy: several said that the intervention was difficult, painful or overwhelming at times.

it was very difficult because it was dabbling into things that I think I'd just really, didn't really even realise were there because ... they were so painful to look at that I didn't really want to so yes it was really tough at the beginning (Katie)

However, the participants commonly felt that this pain was worthwhile. Several participants spoke about pushing themselves to complete exercises they knew they would find uncomfortable for the sake of their recovery.

I was nervous I and I was shaking but I thought I need to start somewhere, I could always say no but that's not going to do any good that's not going to help me
(Matthew)

Experiences of TAU

Allocation ambivalence

While two TAU participants expressed unambiguous disappointment about their treatment allocation, the majority expressed ambivalent views. Some participants spoke about being relieved to be randomised to TAU since they would not have to go through the anxiety

provoking experience of meeting a therapist and disclosing their problems. Others expressed that their disappointment was countered by altruism.

I'll admit to thinking oh maybe that was a bit of a waste of time but ... as a scientist this research may help other people so at the same time as much as I might not have received direct treatment ... you need a control group (Ewan)

No treatment, as usual

The majority of TAU participants described having received little or no professional support since randomisation. In most cases, this continued a narrative of limited or inadequate support prior to their involvement in PRODIGY. Only two participants described receiving specialist mental health support since trial entry, and one of these reported that he was unable to sustain his engagement with this support as low mood and lack of motivation led him to not attend appointments. Several participants reported having received support from their GP but satisfaction with this was generally low. A number of participants expressed frustration that the only treatment option they had been offered by their GP was medication, illustrated by one participant's comment that GPs '*just give you tablets and guide you on your way*' (Max).

'I was the one who had to do everything to help overcome it'

As most TAU participants received limited professional support, they had to manage their mental health independently. Participants who felt that their mental health had not improved or had deteriorated since entering the trial expressed frustration at the lack of support and a sense of having been abandoned ('*I didn't even get a phone call ... I've got no-one*' (Joshua)). However, some participants had achieved considerable improvement in their mental health despite the lack of support and conveyed a sense of pride and achievement at having done this on their own. Asked what was responsible for her improvement, one participant said:

I don't want to sound big headed but I think myself ... I was the one that had to do everything like to help sort of overcome it like sort of thing so and I have done it
(Amelia)

Overarching Themes

'It's just the speaking to someone': the value of talking

Participants from both trial arms emphasised the value of speaking to someone about their problems, many having been reluctant to talk about their problems prior to participating in the trial ('*I realised] talking to people about things isn't a bad thing to do, it actually really*

helps' (Katie)). The noted benefits of talking formed two sub-themes: 'it's not boiled up in me no more' and 'it helped me recognise the things that I wanted to change'. The first sub-theme included descriptions of the way in which talking about problems can provide a sense of release. The second sub-theme encompassed expressions that talking had facilitated greater self-understanding.

it helped to identify little problems that I was having or little symptoms um and I feel like once they'd been identified to you then you can deal with them a lot better
(Ewan)

'Just do it': the importance of activity

Meaningful activity was seen as important by participants from both trial arms. For participants who received SRCBT, 'doing things' was an important element of the intervention. Increasing occupation also appears to have been important for the TAU group with several describing making a concerted effort to increase their activity levels.

doing things that like I wouldn't normally you know stuff that would make me feel really anxious just like I know I have to just do it like regardless of the feelings I've got or thoughts or anything I know I have to just do it (Amelia)

Amongst TAU participants who did not achieve such positive outcomes, continuing inactivity served as a marker of limited progress. Asked to elaborate on his statement that things had got worse for him, one participant responded: '*[I'm] stuck in the house all day doing nothing, just eating and that, just doing nothing*' (Max).

Motivation to change

A determination to make changes was evident in nearly all participants' interviews. This determination was evidenced in participant's willingness to engage with challenging aspects of SRCBT, and in the resolve of members of the TAU group to move forward despite limited support. For a number of participants, high motivation appeared to be related to age: both impending adulthood and relative youth were cited as impetuses for change. The lack of hopelessness in participants' accounts was notable.

I've always had a little bit of fight left inside me no matter what I'm going through, always wanted to be a better person and you know live a normal life, so no matter how depressed or sort of ill so to speak in those terms I can become there's still something inside me that says you will, you need to beat this, you need to carry on

(Liam)

DISCUSSION

The themes identified suggest that participants in the PRODIGY trial found SRCBT acceptable and perceived it to be beneficial. The strength of the therapeutic relationships that developed between therapists and participants, and the flexible way in which the intervention was delivered, appear to have been key to successful engagement of a potentially hard to engage population. Although several participants described the intervention as sometimes difficult, this temporary discomfort was seen as necessary for achieving longer term gains. Participants expressed that the intervention had equipped them with a 'toolkit' of cognitive and behavioural strategies which most, but not all, felt able to use independently after the intervention's conclusion.

TAU participants expressed more mixed opinions of the support received. Most TAU participants reported having received limited professional support and were often dissatisfied with this support. Nonetheless some participants had made considerable gains since entering the trial and conveyed a sense of pride at having made these positive changes independently.

The study's findings indicate that it is possible to successfully engage young people with socially disabling mental health problems in treatment. The surprisingly high motivation to change and low hopelessness expressed by participants suggests that investing in

interventions for young people at this relatively early stage of disorder might pay dividends.

The aspects of SRCBT participants valued mirror priorities for mental health services consistently identified in previous research: for instance the importance of service flexibility and accessibility, and practitioners able to establish supportive relationships with young people¹⁵. However, these consistent messages about what young people want have often failed to translate into service provision¹⁶. Given this, it is perhaps unsurprising that specialist mental health services are accessed by only a small proportion of young people in need¹⁷, reflected in the low mental health service utilisation of the TAU group.

There is an increasing focus in psychotherapy research on acknowledging possible adverse effects of therapy^{18,19}. Qualitative studies of CBT have identified a range of possible negative effects, usually described by study participants as short-term, acceptable consequences of addressing difficult issues²⁰⁻²². Similarly, a number of participants in the present study identified some negative effects of SRCBT. Importantly, these were viewed as short-term and necessary; no participant described sustained negative effects of SRCBT.

Limitations

Since the study was qualitative, the findings cannot be assumed to generalise beyond the setting in which it was conducted. For instance, whilst we found participants were motivated and hopeful, this finding may be specific to those young people willing to engage in a RCT. In addition, although purposive sampling was intended to maximise the likelihood of capturing a wide range of views, it was only possible to select from the subset of

consented trial participants. Those with less positive experiences of trial participation may have been less likely to consent to being approached, resulting in failure to capture certain experiences.

Some members of the study team were involved in the implementation of the RCT and may have unwittingly minimised negative views of trial participation and emphasised positives. We attempted to decrease this risk by remaining cognizant of and reflecting on our potential biases throughout and by involving researchers not involved in the RCT. Further, although efforts were made to encourage participants to express negative views, perceived lack of independence may have discouraged this.

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Tables

Table 1. Demographic and clinical information about participants.

Pseudonym ^a	Age Group	Gender	Group	Site	SCID ^b Research Diagnoses	At risk mental state ^c	Social Functioning ^d
Liam	20-25	Male	SRCBT	Manchester	GAD	No	Very low
Abigail	16-19	Female	SRCBT	Manchester	Depression, Panic disorder, PTSD	No	Very low
Ewan	20-25	Male	TAU	Manchester	Dysthymia, OCD	No	Low
Ben	20-25	Male	TAU	Manchester	Social phobia	No	Very low
Kirsty	16-19	Female	TAU	Manchester	Agoraphobia without panic	No	Very low
Sarah	20-25	Female	SRCBT	Manchester	PTSD, Anxiety disorder not otherwise specified	Yes	Very low
Joshua	20-25	Male	TAU	Manchester	Depression, Agoraphobia, GAD	Yes	Low
Maria	16-19	Female	TAU	Manchester	Depression, OCD	Yes	Low
Katie	16-19	Female	SRCBT	Norfolk	Depression, Specific phobia	Yes	Very low
Emma	16-19	Female	SRCBT	Norfolk	Social phobia, Body dysmorphic disorder	Yes	Very low
Harry	20-25	Male	SRCBT	Norfolk	None	No	Low
Sophia	16-19	Female	TAU	Norfolk	Depression	No	Very low
Matthew	16-19	Male	SRCBT	Norfolk	Depression, Social phobia, GAD	Yes	Low
Bethany	16-19	Female	SRCBT*	Norfolk	Depression, Panic disorder, Social phobia	No	Low
Max	16-19	Male	TAU	Norfolk	Agoraphobia without panic, GAD	No	Very low
Luke	16-19	Male	TAU	Norfolk	Social phobia	No	Very low
Amelia	16-19	Female	TAU	Norfolk	Depression, Panic disorder, GAD	No	Very low

Table 2. Themes identified as characteristic of the experience of SRCBT, TAU and both.

SRCBT	TAU
'She understood me on a personal level': the therapeutic relationship	Allocation ambivalence
Flexibility	No treatment, as usual
'It's given me tools': the CBT toolkit	'I was the one who had to do everything to help overcome it'
No pain, no gain: SRCBT as difficult	
Overarching Themes	
	'It's just the speaking to someone': the value of talking <ul style="list-style-type: none"> - 'it's not boiled up in me no more' - 'it helped me recognise the things that I wanted to change' 'Just do it': the importance of activity Motivation to change

Lived-Experiences of Negative Symptoms in First-Episode Psychosis: A Qualitative Secondary Analysis

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Abstract = 150 words; Text body = 3392

Abstract

Background: Understanding negative symptoms is important given their association with poor outcomes but lived-experiences of negative symptoms in first-episode psychosis have yet to be investigated.

Aim: To explore the lived-experience of negative symptoms through secondary analysis of in-depth interviews conducted with individuals recovering from first-episode psychosis.

Method: Transcripts of in-depth interviews with participants ($n = 24$) recruited from Early Intervention in Psychosis services were analysed thematically with a focus on participants' experiences and personal understandings of negative symptoms.

Results: Descriptions of reductions in communication, social withdrawal, lack of motivation and reduced enjoyment were common features of participants' accounts. Several participants described the experience of having difficulty interacting as like being a 'zombie'. Participants typically attributed these difficulties to medication side-effects, lack of confidence, and avoidance of potential rejection or ridicule.

Conclusions: Personal accounts support the contention that deficit presentations are often underpinned by active psychological processes.

Declaration of Interest: None.

Key words: negative symptoms; psychosis; lived-experience; qualitative research; thematic analysis

Introduction

Negative symptoms are observed across the spectrum of functional psychoses¹ and have been identified as a significant predictor of poor recovery following first-episode psychosis²⁻⁴. They are a treatment priority for many service-users; in a survey of people with lived-experience of psychosis ‘reducing apathy and lack of initiative’ was ranked as the most important treatment goal⁵. However, current treatment options for negative symptoms are limited⁶. Psychosocial interventions for the treatment of negative symptoms show promise⁷ but their development is hindered by our limited understanding of the psychosocial underpinnings of negative symptoms⁸.

The potential for qualitative research to contribute to understanding psychosis has been increasingly recognised^{9,10}. Qualitative methods have been used to explore, among other topics, the phenomenology of psychotic symptoms¹¹⁻¹³, the personal meanings attributed to them¹⁴⁻¹⁶, experiences of treatment¹⁷⁻¹⁹, and the process of recovery^{20,21}. Qualitative investigations of psychosis attempt to prioritise participants’ understandings and interpretations of their experiences. As such, they are able to provide insights into lived-experiences of psychosis and the personal meanings attributed to these experiences.

Little is currently known about personal constructions of negative symptoms since research has rarely examined negative symptoms from the perspective of those with lived-experience. Understanding lived-experiences of negative symptoms has the potential to offer insights into the complex psychosocial processes underlying these presentations, facilitating improved intervention. The current study aimed to explore lived-experiences of negative symptoms

through thematic analysis of in-depth interviews conducted with individuals recovering from a first-episode of psychosis.

Methods

Context

The study involved qualitative secondary analysis of transcripts of in-depth longitudinal interviews conducted for the Super EDEN study (Chief Investigator, MB; Qualitative Lead, AL). Super EDEN followed-up participants in the National EDEN study, a national evaluation of Early Intervention in Psychosis (EIP) services²², for a further two years.

Participants in the study's qualitative component were interviewed every 12 months during the follow-up period. All National EDEN participants were invited to take part in Super EDEN: 518 service-users consented, 207 of whom participated in the qualitative component. The study obtained NHS ethical approval before commencing and adhered to Good Clinical Practice guidelines.

Participants and Sampling

Participants were included in the cohort on the basis of having met the acceptance criteria for a participating EIP service; no special inclusion criteria were imposed. The acceptance criteria of the participating services were in line with the Department of Health's Policy Implementation Guideline and included: presence of a psychotic disorder consistent with an ICD-10 diagnosis F20-29; aged 14 – 35 years; and no previous treatment for a psychotic episode.

A purposive sample of Super EDEN participants was selected for inclusion in the current study. Participants were selected to maximise variation in gender, ethnicity and study site, as well as early negative symptom severity and stability (ascertained by establishing their negative symptom latent trajectory class membership²³). The final sample comprised 24 participants. Participants' demographic characteristics and negative symptom severity scores are presented in Table 1. Pseudonyms are used to protect participant anonymity.

[Insert Table 1]

Data Collection

Interviews explored various aspects of the lived-experience of psychosis, including experiences of symptoms, relationships with family and friends, treatment and recovery. Motivated by a desire to prioritise the interests and concerns of participants and underpinned by the interpretive qualitative framework of medical anthropology^{24,25}, interview schedules were developed iteratively; schedules were amended to reflect themes participants had guided earlier interviews towards. Schedules were developed in collaboration with a panel of young people with personal experience of psychosis.

Written, informed consent was sought before interviews commenced and reconfirmed verbally after completion. Interviews were conducted by trained research assistants, either in the participant's home or a community venue according to participant preference. They were designed to take around one hour but varied in length according to the level of detail participants provided. Interviews were audio-recorded and transcribed verbatim by a professional transcription company.

Analysis

Qualitative secondary data analysis involves utilising previously collected qualitative data to answer new or additional research questions²⁶. Since qualitative data collection is resource intensive and the resulting data often extremely rich, re-use of qualitative data is an important means of making efficient use of limited resources. Ways in which qualitative secondary analysis can generate new insights include ‘prioritising a concept or issue that was present in the original data but was not the analytical focus’ and selecting ‘purposively from the sample used in the original study’²⁷. These strategies were used in tandem in the current study.

The analysis took an inductive thematic approach^{28,29}. Informed by critical realism which recognises that each individual has a unique experience of reality, we sought to understand participants’ realities through close engagement with their individual narratives. Analysis was data-driven with coding drawing on the words used by participants themselves rather than an a priori analytic framework. Initial coding was completed by hand and the codes refined and themes developed with the aid of qualitative data analysis software NVivo³⁰. All transcripts were analysed by the first author and a small number of randomly selected transcripts independently analysed by the second author as a cross-check on the quality of the analysis.

Results

The phrase ‘negative symptoms’ featured in the transcripts only once, but descriptions of experiences corresponding to the negative symptom construct featured in all but four of the participants’ accounts.

'Like a zombie'

Many participants recounted difficulties interacting with others during their episode of psychosis. Participants frequently mentioned that they did not talk as much as usual and some described being unable to express appropriate emotions in response to significant life events. The simile 'like a zombie' was used by several participants when describing these experiences:

"I wasn't moving, I was sitting down ... I wasn't talking. I was just like, you know, like a zombie, just sitting there ... I'd just sit down and not interact with anyone".
Aisha, Birmingham

"Before I was just sitting all day and not speaking at all and not showing any reaction when people were talking to me ... I didn't even like say anything when my sister had a baby. I wasn't even interested. I was just like a zombie".

Jennifer, Lancashire

Through the use of this simile, participants evoked the sense of otherness they experienced. In addition to feeling remote from others, several participants also indicated that they felt remote from themselves. For instance, Callum commented that he was not himself whilst in this zombie-like state:

"I'm a zombie. Like when I'm walking around. People ask me questions and I'm like 'err' ... I'm not me".
Callum, Cheshire

Thus for some participants, disruption in the ability to interact as usual appears to have led to a discontinuity in their identity.

Diminished internal experience

A small number of participants reported reduced internal experience resulting in reduced speech or emotional expression. For instance, Clara explained that she struggled to communicate because she felt 'numb' and 'blocked':

P: "I couldn't really communicate with anybody. Erm it's difficult to describe myself".
R: "Did you feel locked in? Or?"
P: "I didn't feel like detached. And I, I didn't feel like anything".
R: "Sort of empty? Or?"
P: "Yeah. Erm numb. Blocked. My head was sort of blocked. I couldn't think, therefore couldn't speak, because I didn't know what to say".

Clara, Cornwall

For Jennifer, a lack of emotional expression was symptomatic of an inability to experience strong emotions:

"I'd been not been able to have any feelings or anything and just like except to have feelings of anxiety but I didn't have feelings like that. Do you know that twin towers, when it crashed, I didn't care. I sat watching it, I was like, oh yeah boring. But now, when I watch programmes on it, I was nearly crying because I was like oh it's so dramatic and emotional and everything. But I remember distinctly when it happened, I just sat there staring ... I didn't have any feelings for any of it. It was horrible. It was like I'd been possessed by a demon or something, it was really weird. It was like I wasn't even in my own body".

Jennifer, Lancashire

Similarly, some participants explained decreased motivation as a consequence of a profound reduction in their enthusiasm for life:

"it's harder for me to enjoy [activities] because you do feel like you've had so much sucked out of you that, it's like that inner child it's a bit like someone's taken it by the neck, strangled it, it's just survived and then shaken it again and then said, right your life's never going to be the same again ... we go to the park, we go out for lunch, we go into town and go to groups or whatever and I do do that but just not with as much gusto as I did before".

Isabella, Cambridgeshire

Such accounts align with psychiatric characterisations of negative symptoms, which take reductions in expression and activity to be indicative of limited emotional range, reduced capacity for thought, lack of drive and reduced hedonic capacity. However, diminished internal experience was described by only a minority of participants who reported reductions in expression, motivation or sociability.

Medication side-effects

The explanation for decreased expression, motivation and sociability most frequently given by participants was that these were side-effects of prescribed medications. Participants commented that the sedative effect of medication decreased their drive to engage in activities requiring relatively more effort and energy. Some participants described a trade-off between controlling positive symptoms and the negative impact of sedation on their ability to socialise and participate in activities:

"Because my thoughts were racing in really weird directions, they thought that a more sedative tablet would be better for me. But, of course, then that meant that I wasn't going out very much. I wasn't socialising. I wasn't really doing the things that may have helped me, you know, in the other part, the not medication part".

Hayley, Cornwall

For other participants, lack of motivation was not seen as a direct side-effect of medication but of weight-gain associated with use of antipsychotics:

"I feel like the heavier I am, the more harder for me to move around. And when I was lighter I was more active and doing loads of things and I had motivation and everything. And now like - my motivation - like before I had loads of motivation. Now that my motivation isn't really there. It's like someone has to push me to do things".

Aisha, Birmingham

'A confidence thing'

Lack of self-confidence was another explanation participants gave for decreased expression, motivation and sociability. For Yasmin, this lack of confidence was linked to her behaviour during her episode of psychosis:

"I don't talk to anybody that much and I haven't got confidence left in me, because I think, 'Oh, my God.' I'm not sure about things which I'm doing. Like, am I not, am I doing right or not, because, you know, like, when you're unwell, you don't realise, do you? So it made me think, like, I've got no confidence, like, I don't know if what I'm doing is right or wrong".

Yasmin, Lancashire

Yasmin talked at some length about her experience of behaving in ways that she afterward viewed as inappropriate and thus experiencing crippling doubt about even simple everyday activities and interactions. She expressed that she no longer made plans for the future because she felt she wouldn't be capable of carrying them out.

Whilst Yasmin described a global lack of confidence, for other participants their lack of confidence was specific to a certain domain. For instance, Clara discussed her reluctance to engage in "intellectual" conversations due to reduced confidence in her cognitive capacities:

"I found it very difficult to learn again when I started to get back into things. I couldn't process information ... an intellectual conversation with someone, that scares me because I feel like I don't know. And perhaps that's a confidence thing. I know things that they don't know perhaps, but it just seems like I don't have that, that way of being able to process information or to capture the - to have that information that I had before".

Clara, Cornwall

Active avoidance

Participants often presented social withdrawal as a deliberate strategy, intended to protect them from rejection or ridicule. Several participants spoke about deliberately cutting contact with friends or making fewer efforts to form new friendships than they would have done before experiencing psychosis:

"When I had the psychosis and the problems I cut myself off from a lot of people, I withdrew and I lost a lot of friends through that".

John, Birmingham

"[I'm] perhaps not so likely to take the risk to get to know a lot more people I think. I tend to sort of see what happens and go with that rather than sort of try and make more, try and widen my social circle by talking to more people ... before [the psychosis] I think perhaps I'd be a bit more keen to sort of get to know people better and perhaps be a little bit more intent on making friends I suppose in that way".

Isabella, Cambridgeshire

For Isabella, getting to know new people following her psychotic episode was a risk where before it had been an opportunity. Isabella was aware that her strategy of protecting herself through putting 'the boundaries up' had resulted in a smaller social network but saw this as a price worth paying for avoiding 'trouble'.

Some participants linked their decision to withdraw to the stigma surrounding psychotic disorders. For instance, Ben explained that his withdrawal from friendships was connected to the shame he felt about his psychosis:

"My relationship with, erm, quite a few of my friends has changed in a negative way, and it's not been because of prejudice or lack of understanding on their part, it's because at first I felt very ashamed, and I deliberately cut them out of my life".

Ben, Birmingham

In common with Ben, participants generally expressed that it was not stigma from others, but internalised stigma or fear of stigma which contributed to their withdrawal. Participants were often acutely aware of negative media portrayals of psychosis and this fed their fears about how others would perceive them. Aidan, who had lost contact with all his former friends expressed that he believed others would find him '*disgusting*' if they knew about his symptoms.

Shame and stigma were also key to some participants' decisions to avoid romantic relationships. Several participants shared Jennifer's dilemma:

"It'd be really really hard to establish a relationship because you wouldn't know when to say to them, 'I've got schizophrenia' because if you leave it too late, they'll say, 'Oh why didn't you tell me, you've led me on.' And if you say it too soon, they'd never even speak to you because they'll just assume you're mad and it's very very, that's very difficult".

Jennifer, Lancashire

Jennifer had ruled out the possibility of forming an intimate relationship and consequently believed she would never be in a position to marry or have children. Negative symptoms measures often consider lack of intimate relationships in individuals with psychosis to be indicative of diminished capacity for emotional closeness. Jennifer's account offers the alternative explanation that some people with experience of psychosis may have given up hope of fulfilling their desire for an intimate relationship due to the perceived impossibility of establishing one.

Some participants employed a strategy of avoidance in order to escape negative evaluation of their changed appearance following medication induced weight-gain. For instance, Clara

explained that her weight increased rapidly whilst on antipsychotic medication and, as a result, she avoided social situations in order to protect herself from the critical gaze of others:

P: "I think that [weight-gain] gave me a lot of the anxiety I had from err not going out, not wanting to see anybody that I knew, because I had my episode and was in the ward in London, then came back down. No one knew what had happened to me, but I was huge and I wasn't talking to anyone".

R: "Okay. So it made you more socially isolated?"

P: "Oh yeah. I didn't want anyone to see me like that. I know it's sad, but I really didn't".

Clara, Cornwall

Clara described her fear that her sudden weight-gain would alert people to her use of antipsychotics, thus exposing her to the stigma associated with psychosis.

Discussion

In a purposive sample of EIP service-users who presented with varied negative symptom severity and stability during their first-episode of psychosis, experiences corresponding to the negative symptoms construct commonly featured in accounts of the experience of psychosis. Participants' narratives challenge the widespread framing of negative symptoms as passive manifestations of diminished capacity and display the often profound personal and social impact of the experience of negative symptoms.

Several participants used the simile 'like a zombie' to describe their experience of having difficulties interacting with the world around them, evoking a sense of otherness. For some, this experience led them to feel remote not only from other people, but also from themselves. Such accounts suggests that European phenomenological approaches to psychosis³¹ may continue to be of relevance in understanding the subjective experience of negative symptoms. These approaches suggest that negative symptoms are not straightforward deficit states but

are instead characterised by positive experiential disturbances stemming from core disturbances in the sense of self³².

Participants offered varying explanations of the negative symptom-like experiences they described. Consistent with research carried out with individuals with more chronic psychosis^{11,33}, reduced communication and lack of motivation were often viewed as medication side-effects. As such, it is possible that the experiences described by some participants do not relate to primary negative symptoms but to negative symptoms secondary to medication side-effects.

Some participants described decreased emotional experience, capacity for thought or drive as lying behind changes in their behaviour. This finding echoes Krupa et al.'s³⁴ report that some individuals recovering from psychosis describe a deadening of emotions and increased apathy, turning participation in previously valued activities and social interactions into experiences to be endured. Participants also identified lack of confidence as a reason for negative symptom-like behaviour. Previous psychotic symptoms and the perception of decreased cognitive capacities undermined participants' confidence in their abilities, leading to decreased activity and interaction. This finding supports quantitative evidence that pessimistic assessments of cognitive and social capabilities may be implicated in negative symptom maintenance^{35,36}.

Active avoidance was also frequently recounted. Several previous studies have identified withdrawal as a strategy used by individuals experiencing psychosis to minimise potential embarrassment or rejection^{33,37-39}. The apparent contribution of internalised and perceived stigma to some participants' active avoidance is in accord with previous research suggesting

that withdrawal is a common reaction to feeling excluded from society as a result of mental health problems³³. These findings highlight the role of agency in negative symptom presentations, echoing Corin's reframing of negative symptoms as 'positive withdrawal'⁴⁰: a recovery strategy characterised by the deliberate maintenance of distance from normative social roles and relationships. They also intersect with cognitive models of negative symptoms which contend that apparent deficit presentations are often underpinned by active psychological processes^{41,42}.

Limitations

Since the study used qualitative secondary analysis, participants were not specifically asked about their experience of negative symptoms. Had an interview schedule specifically designed to elicit accounts of negative symptoms been employed, further insights might have been gained. However the use of secondary data also conferred advantages, making it possible to observe the extent to which negative symptoms were brought up spontaneously and the explanatory frameworks used by participants themselves.

The timing of data collection could also be considered a limitation. Participants were interviewed for the first time towards the end of their time with EIP or following discharge, in some cases several years after their index episode. It is possible this hindered participants' ability to recall their experiences. However, time having passed since the onset of their psychosis might also have afforded participants more time to reflect on their experiences.

Clinical Implications

The findings indicate the potential value of exploring clients' personal understandings of their negative symptoms and suggest that particular attention should be paid to the possible impact of medication side-effects, diminished internal experience, low self-confidence and avoidant coping strategies. Clinicians should also consider the possible contribution of internalised stigma to negative symptom presentations. That participants often described active psychological processes as underpinning the negative symptom-like experiences they described supports the potential for tailored psychological interventions to ameliorate negative symptoms.

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Author Contributions

BG was involved in designing the study, analysed and interpreted the data, and wrote the first draft of the manuscript. JH, DF and CN were involved in designing the study, supervised data analysis and contributed to data interpretation. AL wrote the topic guides, carried out purposive sampling of participants and contributed to data interpretation. MB, AL, NF, PBJ, SPS, LE, TA, MM, VS, JS, JH and DF were responsible for the conception, design and

delivery of the Super EDEN study. All authors have contributed to and approved the final manuscript.

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Tables

Table 1. Sample demographic characteristics and mean negative symptom severity scores

Pseudonym ^a	Study Site	Ethnicity	Age ^b	Mean Negative Symptom Score ^c		
				Baseline	6M	12M
Daniel	Norfolk	White British	20	4.00	4.43	4.00
Max	Cheshire	White British	27	4.00	3.43	2.71
Nathan	Birmingham	White British	26	3.43	3.29	2.57
Yasmin	Lancashire	Asian Pakistani	28	1.57	3.29	2.57
Tom	Cambridgeshire	White British	20	1.71	2.29	2.14
Hayley	Cornwall	White British	28	3.00	2.86	2.86
John	Birmingham	White British	31	2.57	3.00	2.57
Jacob	Birmingham	Black Caribbean	28	3.43	3.43	1.00
Aisha	Birmingham	Asian Pakistani	28	3.29	2.00	1.43
Oliver	Cornwall	White British	30	3.14	1.29	2.00
Stacey	Cornwall	White British	27	4.29	2.29	1.29
Aidan	Norfolk	White British	25	3.00	3.43	2.14
Steve	Lancashire	White British	27	2.86	3.71	2.14
Philip	Norfolk	White British	37	1.00	1.29	1.29
Nazir	Lancashire	Other Asian	21	2.29	2.29	1.86
Alexander	Devon	Other White	32	1.00	2.57	1.00
Shelly	Birmingham	Black Caribbean	28	1.29	1.57	1.29
Isabella	Cambridgeshire	White/Asian	35	1.57	1.14	1.14
Jennifer	Lancashire	White British	30	2.14	1.57	1.00
Ben	Birmingham	White/Caribbean	27	2.43	1.57	1.14
Kelly	Norfolk	White British	22	1.43	1.57	1.71
Clara	Cornwall	White/African	30	2.14	1.00	1.00
Jack	Cambridgeshire	White Irish	29	1.71	1.00	1.00
Callum	Cheshire	White British	27	1.14	1.00	1.00

^aPseudonyms are used throughout to protect the anonymity of participants.

^bAge at initial interview.

^cMean negative symptoms score (min 1; max 7) for the seven PANSS items ('blunted affect' (N1), 'emotional withdrawal' (N2), 'poor rapport' (N3), 'passive social withdrawal' (N4), and 'lack of spontaneity and flow of conversation' (N6), 'motor retardation' (G7) and 'active social avoidance' (G16)) found to indicate the negative symptoms construct in a factor analysis of PANSS data from the EDEN cohort.