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**The negative symptoms of psychosis:
A psychological perspective of their
treatment and impact on parental carers.**

Imogen Spurling

A thesis submitted in partial fulfilment of the requirements for the
degree of Doctor of Clinical Psychology

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Declaration

This thesis was carried out under the supervision of Dr Elizabeth Newton, Clinical Psychologist, Dr Adrian Neal, Clinical Psychologist and Dr Mark Bernard, Clinical Psychologist. Participants were recruited from Birmingham and Solihull Mental Health NHS Trust. Apart from collaboration with the above people, this thesis is my own work. This thesis has not been submitted for a degree at another university.

The authorship of the papers will be shared with the above named individuals. Chapters one and two have been written for submission to Psychology and Psychotherapy: Theory, Research and Practice (see Appendix J for Notes for Contributors). Any deviation from the journal word limit was for the purpose of thesis submission and will be adhered to for journal publication.

Summary

The negative symptoms of schizophrenia have a significant effect both on the lives of those experiencing them and their carers. Despite their recognition as a core element of the illness, there has been relatively little research focusing on their impact and amelioration, from a psychological perspective, compared with the positive symptoms of schizophrenia. This thesis includes three chapters: the first, a literature review, examines the effectiveness of psychosocial interventions targeting the negative symptoms of schizophrenia. The studies reviewed are divided into three broad categories (activity based therapy, cognitive behavioural therapy and integrated therapy) and the empirical contribution of each is examined in relation to its methodological strengths and weaknesses. The second chapter, an empirical paper, explores the impact of negative symptoms on parental carers of those experiencing these symptoms during early psychosis. The analysis of interviews with six parents revealed two superordinate themes, the clinical and research implications of which are discussed. The third chapter is a reflective account of the research process in relation to both personal and professional learning.

Chapter One: Literature Review

**A systematic review of psychosocial interventions
specifically targeting the negative symptoms of
schizophrenia: efficacy and recommendations for
the future.**

Word Count (excluding titles, tables and references): 7923

**Paper prepared for submission to Psychology and Psychotherapy:
Theory, Research and Practice
(See Appendix J for notes to contributors)**

1. Abstract

Negative symptoms of schizophrenia are highly prevalent; they are predictive of poor prognosis and account for much of the functional disability that is associated with schizophrenia. However, they show a poor response to pharmacological treatments and, despite indications of the potential efficacy of psychosocial interventions for negative symptoms in research intending to ameliorate positive symptoms, there has been little research into psychosocial interventions that specifically target negative symptoms of schizophrenia. This review critically and systematically evaluates the small body of literature investigating the effects of psychosocial interventions targeting negative symptoms. The interventions are reviewed in three categories: activity based therapy, cognitive behavioural therapy and integrated therapy. Many of the studies reviewed are methodologically flawed and comparison of results is complicated by the diversity of interventions as well as by variation in participants' stage of illness and symptom severity. However, some of the reviewed literature provides preliminary evidence for the feasibility, efficacy and acceptability of psychosocial interventions for negative symptoms. Further research is required in order to support this mixed and tentative evidence, as well as to develop and evaluate new treatments specifically targeting negative symptoms of schizophrenia.

2. Introduction

2.1 Definitions and terminology

The diagnostic criteria for schizophrenia, set out in the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV, APA, 1994), includes the occurrence of two or more of the following five characteristics: delusions, hallucinations, disorganised speech, grossly disorganised or catatonic behaviour (positive symptoms) and negative symptoms experienced for “a significant portion of time during a one-month period”. Negative symptoms are based on the concept of deficit, describing a reduction or absence of behaviours considered to be “normal”. The DSM-IV uses the term to describe “restrictions in the range and intensity of emotional expression (affective flattening), in the fluency and productivity of thought and speech (alogia) and in the initiation of goal-directed behaviour (avolition)” (APA, 1994, 275). It also discusses other negative symptoms, such as the diminished capacity to experience pleasure (anhedonia) and social withdrawal. Similarly, the International Classification of Diseases (ICD-10, 2002) describes negative symptoms as “marked apathy, paucity of speech, and blunting or incongruity of emotional responses” (ICD-10, 2002, 78).

Carpenter et al. (1985, 1988) made the distinction between primary and secondary negative symptoms, suggesting that, whilst the observable phenomena of both types of symptoms are the same, they differ in aetiology. Primary negative symptoms are persistent, believed to be idiopathic to the illness, and appear long before people seek treatment, during the prodromal phase of illness; whilst secondary negative symptoms are thought to be transitory and caused by other factors, such as a reaction to the psychotic process, medication side effects, social deprivation,

depression or anxiety. Carpenter et al. (1988) also proposed the concept of the “deficit syndrome” to describe primary negative symptoms that are also enduring over time.

2.2 Conceptual validity

Bentall (1990, 2003), Boyle (2002), Pilgrim (1990) and, more recently, Van Os (2009), have challenged the concept of “schizophrenia” as a unified syndrome and questioned its reliability and validity as a diagnostic entity. Read, Moshier and Bentall (2004) contest the medical model and bio-genetic theories of “schizophrenia” and discuss evidence that the diagnosis has failed to demonstrate validity in symptomatology, outcome, aetiology and response to treatment.

The distinction between positive and negative symptoms is also controversial and some have criticised it as over-simplistic, as well as questioning the validity and reliability of the constructs (Andreasen et al., 1995)¹. However, others argue that the negative symptom construct has good reliability, supported by well-replicated findings that the symptoms are related to other constructs, such as poor premorbid functioning and poor performance on neuropsychological tests, as well as having good predictive and discriminant validity (Earnst & Kring, 1997). The positive/negative distinction has also been supported by findings from studies, conducted in many cultures across the world, using factor analysis, which have frequently demonstrated that symptoms of psychosis fall into three independent clusters: positive symptoms, negative symptoms and symptoms of cognitive disorganisation (Read, Moshier and Bentall, 2004; Stolar & Grant, 2007).

¹ Boyle (2002) discusses evidence that challenges the concept of negative symptoms, such as variability in its definition and lack of internal consistency of scales used to assess and measure the symptoms.

Furthermore, the distinction has been supported by studies investigating the course and treatment response of symptoms in each dimension, finding that positive symptoms are often episodic and responsive to medication, whereas negative symptoms tend to be more stable and less responsive to medication, suggesting that different pathophysiological processes underlie each symptom group (Crow, 1985; Kirkpatrick et al., 2001).

It has been argued that negative symptoms are a behavioural consequence of cognitive deficit, whilst more recent evidence suggests that cognitive and negative symptoms may be separate domains (Stahl & Buckley, 2007). The distinction between affective and negative symptoms is also unclear², with some arguing that there is an overlap in features of depression and negative symptoms (Siris et al., cited in Halari et al., 2009), whilst other findings suggest they represent two separate domains (Baynes et al., 2000 cited in Halari et al., 2009).

For the purposes of this review, the terms “schizophrenia” and “negative symptoms” will be used; however, both present a considerable conceptual and terminological challenge that has resulted in much debate and division of opinion since their original conceptualisation, and which continues today.

2.3 Aetiology of negative symptoms

The separation of negative and positive symptoms into distinct groups of symptoms is important as they may have different aetiologies and may therefore respond differently to treatments (Stahl & Buckley, 2007). Several models have been

² Bentall (2003) discusses studies that suggest that negative symptoms, such as flat affect, may reflect difficulties expressing rather experiencing emotions.

proposed in an attempt to explain the occurrence of negative symptoms of schizophrenia.

It has been suggested that genetic and obstetric factors, resulting in enlarged ventricles, may be more directly related to the development of negative symptoms than positive symptoms (Rector et al, 2005). Other research has postulated the relationship between negative symptoms and neurotransmitters, for example, decreased dopaminergic activity (Mackay, 1980) and increased cholinergic activity (Tandon & Gredon, 1991). Studies have also reported a relationship between negative symptoms and decreased frontal lobe activity and blood flow, as well as decreased metabolism of other areas of the brain including the parietal and temporal cortex and the thalamus (Earnst & Kring, 1997; Andreasen et al., 1992; Lewis et al., 1992). Structural abnormalities, such as grey and white matter loss in several areas of the brain (Sigmundsson et al., 2001), and brain volume (Matsumoto et al., 2001; Rajarethinam et al., 2001) have also been linked to negative symptoms. However, it remains unclear as to which part or parts of the brain might be involved as, due to the heterogeneity of schizophrenia symptoms, studies rarely include samples of people experiencing negative symptoms alone. Such research has also been criticised as reductionist and limited by its disregard of the effects of environmental, social and psychological factors on aetiological processes (Bentall, 2003).

A number of studies have demonstrated associations between deficits in cognitive functioning, as assessed by neuropsychological test performance, and negative symptoms (Andreasen & Olsen, 1982; Frith, 1992; Light et al., 2003). Consistent with the reported relationship of brain metabolism and structural abnormalities and

negative symptoms, an association between negative symptoms and poor frontal lobe functioning has been found. Frith (1992, 1995), for example, suggests that negative symptoms such as avolition and social withdrawal can be explained by an impairment in the ability to put plans into action. However, it remains unclear as to whether, or to what extent, negative symptoms and cognitive dysfunction are independent processes (Bell & Mishara, 2006). Although there is no consensus about any core neuropsychological deficit, it has been hypothesised that interventions that focus on cognition might improve negative symptoms.

It has also been suggested that the experience of schizophrenia could be viewed as a trauma and that negative symptoms might be explained as part of a post-traumatic stress response (Birchwood, Fowler & Jackson, 2002). Characteristics of posttraumatic stress disorder (PTSD) include a lack of interest in activities, restricted range of affect, and feelings of detachment from others, which are all similar to negative symptoms of schizophrenia³. However, Meyer et al. (1999) suggested that whilst trauma may play a role in the development of negative symptoms, it is unlikely to be a major cause. The theory has several limitations, for example in its inability to account for all negative symptoms, such as under-arousal.

2.4 Impact of negative symptoms

Makinen et al. (2008) suggest that one in three people with schizophrenia suffer from negative symptoms. Negative symptoms appear resistant to antipsychotic medication⁴, with pharmacological treatments demonstrating only modest effects

³ Although it is possible to discount pseudo negative symptoms as a result of trauma through a thorough assessment.

⁴ Negative symptoms appear to respond better to novel atypical antipsychotics than to classical antipsychotics, but the response rate is still low (Davis, 2003 cited in Klingberg et al., 2009).

(Buchanan, 2007). It has also been suggested that greater severity of negative symptoms is related to poor medication compliance (Tattan & Creed, 2001). Individuals with predominantly negative symptoms have been shown to have a worse long-term prognosis than those with predominantly positive symptoms (Andreasen et al., 1982; Barnes & Liddle, 1990; Tandon & Gredon, 1991). Negative symptoms have been described as the “most unrelenting and disabling features” of schizophrenia, causing severe burden both to service users and their carers (Winograd-Gurvich et al., 2006).

A wealth of research has supported the relationship between negative symptoms and functional difficulties, such as psychosocial and community functioning (Breier et al., 1991; Sayers et al., 1996). Symptoms, such as amotivation and social withdrawal, for example, interfere with peoples’ ability to engage in interpersonal and social interaction and in other activities required for community functioning, resulting in poor social outcome (Pratt et al., 2005). Hamilton et al. (1989), Macdonald et al. (1998) and Thorup et al. (2006) found that negative, but not positive symptoms, affect social skills and are associated with social network disruption. Negative symptoms have also been associated with vocational impairment (Glynn et al, 1992; Lysaker & Bell, 1995), shown to predict poorer quality of life early in the course of schizophrenia, and to be positively and significantly correlated with financial dependence on others and impaired ability to enjoy recreational activities (Ho et al., 1998).

2.5 Effects of psychosocial interventions on negative symptoms

There is a large and growing body of research that demonstrates the effectiveness of psychosocial interventions for positive symptoms of schizophrenia. Many studies have demonstrated the effectiveness of cognitive behaviour therapy (CBT) for schizophrenia (Garety et al., 1994; Gaudiano, 2005; Wykes et al., 2008), resulting in the inclusion of CBT in the National Institute for Clinical Excellence (NICE) guidelines for schizophrenia (2002). As well as demonstrating improvements in positive symptoms, a number of studies have reported significant effects of psychosocial interventions on negative symptoms as a secondary outcome. Pinto et al. (1999), Tarrrier et al. (2001), Sensky et al. (2000) and Haddock et al. (2003), for example, conducted randomised controlled trials of CBT for positive symptoms and reported significant effects on negative symptoms.

Wykes et al. (2008) recently conducted a meta-analysis into the efficacy of CBT for psychosis (CBTp), a treatment designed to target positive symptoms of schizophrenia. 34 clinical trials were assessed, and although only two investigated the effect of treatment on negative symptoms as a primary aim, 24 reported effects on negative symptoms as a secondary outcome. CBTp is reported to have had modest effects on both positive and negative symptoms, with the effect size actually greater for negative symptoms ($d=0.44$) than for the positive symptoms it was targeting ($d=0.32$) (Wykes et al., 2008).

2.6 Lack of research into psychosocial treatments for negative symptoms

Since Kraepelin (1913) and Bleuler's (1911) original descriptions of schizophrenia, negative symptoms have been viewed as core and characteristic elements of the

illness. Despite their association with functional impairment, and despite the strong indication of the potential efficacy of psychosocial interventions for the reduction of negative symptoms, there has been little investigation of the efficacy of treatments specifically targeting negative symptoms. In 1985 Carpenter et al. described research into the treatment of primary negative symptoms as “sorely needed” (p.447) and the “greatest current challenge to those responsible for the care of the schizophrenic patient” (p. 447). However, in 2009 the American Psychological Association (APA) stated that “there are no treatments with proven efficacy for primary negative symptoms” (APA, 2004 cited in Klingberg et al., 2009, p. S150). The need for interventions that specifically target negative symptoms has been described as “an important treatment priority” (Pratt et al., 2005, p.196).

The relative lack of research into treatments for negative symptoms may be due to the lack of clarity about the validity of negative symptoms as a concept and insufficient understanding of their nature and complex aetiology. Crow (1985) suggested that the presence of negative symptoms is predictive of a poor response to psychosocial treatment and Halford and Hayes (1991) discuss the fact that negative symptoms may not respond to psychological interventions if they are the result of neurological impairment.

There are also intrinsic difficulties with conducting research with those suffering from negative symptoms. Research into the treatment of negative symptoms may have been limited by difficulties recruiting participants to studies. Individuals with negative symptoms are often unaware of their symptoms (Selten et al., 2000), thus symptoms may only be reported if caregivers are concerned by them. However, as

the reductions in normal behaviours that characterise negative symptoms can be subtle, they may be less obvious, or viewed as less important than positive symptoms by caregivers (Stahl & Buckley, 2007).

Once identified as a concern, the assessment and measurement of negative symptoms can also be difficult due to their subtlety and complexity (Stahl & Buckley, 2007). Whilst positive symptoms are more easily identified, negative symptoms may be confused with affective symptoms and cognitive impairment (Moller, 2007). The most commonly used scales are the Scale for the Assessment of Negative Symptoms (SANS) (Andreasen, 1984) and the Positive and Negative Symptom Scale (PANSS) (Kay et al., 1989). Although both are well established and useful tools for quantifying negative symptom change, they may be difficult to use in clinical trials due to the length of time needed to administer and score them (Cohen et al., 2008). Current negative symptom rating scales have also been shown to require a great deal of training in order to achieve inter-rater reliability, and may not detect subtle changes in symptoms over time (Cohen et al., 2008).

There has been much debate over the importance of distinguishing between primary and secondary negative symptoms in the design of trials to assess treatment for negative symptoms (Stahl & Buckley, 2007). However, in order to distinguish primary and secondary symptoms, information about the longitudinal course of symptoms would be required and detailed assessments would be necessary (Buchanan, 2007).

By their very nature, negative symptoms can hinder clients' engagement in therapy, including participation in research studies (Stolar, 2004). In addition, Dyck et al. (2000) discuss the tendency of research studies to select participants while they are inpatients in the acute stage of their illness experiencing high levels of positive symptoms, perhaps obstructing a focus on negative symptoms.

2.7 Recent developments-Potential Role for Psychosocial Interventions

The recent National Institute of Mental Health (NIMH) MATRICS initiative (Measurement and Treatment Research to Improve Cognition in Schizophrenia, 2006) attempted to stimulate interest and research into the development of new medications to treat negative symptoms. Whilst beneficial in highlighting the need for research into treatments for negative symptoms, the NIMH-MATRICES Consensus Statement on Negative Symptoms (Kirkpatrick et al., 2006) has also been criticised for its failure to recognise the need for the development of psychosocial interventions (TARRIER, 2006). TARRIER (2006) highlights the necessity for development of psychological models to explain negative symptoms and for non-drug treatment approaches.

The recently updated NICE guidelines for schizophrenia (2010) report the effectiveness of "arts therapies" in the reduction of negative symptoms in both inpatient and outpatient populations. The guidelines recommend the use of arts therapies particularly for those suffering from negative symptoms on the basis that they are "currently the only interventions (both psychological and pharmacological) to demonstrate consistent efficacy in the reduction of negative symptoms" (p.256). The guidelines do not include discussion of the evidence suggesting the potentially

beneficial effects of CBT for negative symptoms, as reported by Wykes et al. (2008) and base their recommendation on a review of only six studies, many of which are methodologically flawed and which span an array of treatment modalities, including music, art and body-oriented therapies. Thus, whilst suggesting the potential efficacy of arts therapies for negative symptoms, the guidelines advocate the need for further research. Three of the studies reviewed in the NICE guidelines (2010) review (Richardson (2007), Rohricht (2007) and Ulrich (2007)) are included in this review⁵, and are discussed in section 5.1.

Recently there have been several studies published which attempt to evaluate psychosocial interventions specifically targeting negative symptoms (Klingberg et al., 2009; Perivoliotis & Cather, 2009; Johnson et al., 2009). Given the prevalence, and extremely disabling impact of negative symptoms, there is a need to review this evidence base, in order to guide services in their delivery of psychosocial interventions to those experiencing negative symptoms of psychosis. Therefore, these recent publications, and the small but significant body of earlier literature investigating the targeted effects of interventions on negative symptoms, will form the focus of this review.

3. Aims of the literature review

This review aims to examine the effectiveness of psychosocial interventions for negative symptoms of schizophrenia. In particular, it will evaluate the existing literature on interventions that target the reduction of negative symptoms of schizophrenia as a primary outcome. Johnson et al. (2009) suggest that psychosocial

⁵ The remaining papers were excluded as they did not meet the inclusion criteria for this review.

treatments for negative symptoms can be divided into three groups: activity-based therapy, cognitive-behavioural therapy (CBT) and integrated therapy (IT). This review will examine the literature in accordance with these categories. The review will also consider areas for future research.

4. Literature Search Strategies

The literature search sought to identify all published research that had investigated psychosocial interventions with a particular focus on ameliorating the negative symptoms of schizophrenia. The following databases were searched: PsycINFO, OVID, PsycARTICLES, CINAHL, Medline and the Cochrane Library, as these were the databases identified as being most relevant to the research area. In addition, reference lists of all retrieved papers and related papers were hand searched to identify any additional studies. The literature search was carried out in March 2008 and repeated at regular intervals until January 2010. The search terms included: negative symptoms, psychological, psychosocial, intervention, treatment, therapy, psychosis and schizophrenia.

4.1 Inclusion and exclusion criteria

For inclusion, studies were required to be published in an English language, peer reviewed journal. Studies were required to apply a psychosocial intervention⁶ with a specific focus on the amelioration of negative symptoms of schizophrenia. Studies that reported the effect of an intervention on negative symptoms as a secondary outcome were excluded as they were numerous and their inclusion would have been

⁶ The definition of psychosocial intervention used for this review included psychological treatments (e.g. cognitive behavioural interventions and psychoeducation), social interventions (e.g. community based treatments) and arts therapies (e.g. art, music and body-oriented therapies) and included interventions delivered to individuals, groups and families.

beyond the scope of this review. The initial search returned 502 papers which were potentially relevant. The abstracts of these papers were read and 431 were excluded as they did not meet the inclusion criteria for review. Full text copies of the remaining 71 papers were obtained and reviewed, resulting in a further 54 being excluded for the following reasons: not published in an English language and/or peer reviewed journal (N=5), no psychological or psychosocial intervention (N=11), intervention was unspecific and/or the specific effect on negative symptoms was not discussed (N=12), negative symptoms reported as a secondary outcome (N= 26). A final sample of 17 papers met all inclusion criteria.

Table 1. Papers reviewed

1. Activity based therapy						
Author	Diagnostic criteria/sample	Experimental intervention	Control condition	Design, duration, outcome measures	Rationale for intervention/study aims	Main findings
Johnson <i>et al.</i> 2009	Schizophrenia, schizoaffective disorder and psychotic disorder NOS N = 3	Loving-Kindness Meditation	No control	Case studies 6 sessions of 60 minutes, weekly. Review session 6 weeks after final session Assessments of psychiatric symptoms, emotions and psychological recovery	Proposes the applicability of LKM to negative symptoms. Some evidence that, by increasing positive emotions, LKM may improve anticipatory pleasure, which may be a specific deficit in anhedonia and asociality found in people with negative symptoms.	Describes potential benefits, challenges and feasibility of intervention as demonstrated by 3 cases.
Rohricht & Priebe, 2006	DSM-IV schizophrenia N = 45	Body-oriented psychological therapy	Supportive counselling	RCT 20 sessions of 60-90 minutes, twice weekly PANSS, EPS, SQOL, MANSA, CAT, HAS	Given the non-cognitive nature of certain negative symptoms e.g. emotional withdrawal and motor retardation, paper hypothesises that such symptoms may respond to non-verbal methods combining sensory awareness techniques. Report first trial of BPT for negative symptoms.	Patients in BPT attended significantly more sessions than SC, and significantly lower negative symptoms scores after treatment.
Ulrich <i>et al.</i> 2007	ICD-F20-F29	Music therapy	Standard	RCT	Study attempts to replicate	No significant difference in

	Psychotic disorders N = 37		treatment	Average of 7.5 sessions (SD 3.5) /1.6 sessions a week of 45 minutes GTS GTFm SANS	findings from three Asian studies that music therapy has effects on negative symptoms, with a European sample.	decrease in negative symptoms between two groups. Trend suggested decrease in negative symptoms higher in MT group. However, after sensitivity analysis for schizophrenia subgroup, there was a significant difference in negative symptoms between groups.
Richardson <i>et al.</i> 2007	Chronic schizophrenia N = 91	Art therapy in addition to Standard Psychiatric Care	Standard Psychiatric Care	RCT 12 sessions of 1.5 hours, weekly HONOS Scales, BPRS,SFS, IIP,SANS, Perc QoL, BSI	Art therapy proposed to be suited to those with negative symptoms due to non verbal nature. However, there is little controlled evidence. Study presents RCT of AT.	Only statistically significant effect of AT was on SANS. Art therapy found to reduce negative symptoms.
Dobson <i>et al.</i> 1995	Schizophrenia N = 28	Social skills training	Social milieu treatment	RCT One week assessment period + Four one hour sessions per week for nine weeks + Another week assessment period SCID PANSS	Positive correlation of negative symptoms with social skills deficits. Lack of research into effects of social skills training. Study hypothesises that intervention will have a greater effect on negative than positive symptoms.	Both treatments effective in reducing combined PANSS scores, positive and negative symptoms. Soc Skills group: Negative symptom scores significantly reduced at 3, 6 and 9 week assessments during treatment but not at 3 or 6 month follow up. Negative symptom scores increased in Soc Skills group at 6 month follow up. Soc Mil group: Negative symptom scores significantly reduced at 3

						weeks assessment and at 3 month follow up, but not at 6 or 9 week assessment.
Hayes <i>et al.</i> 1995	DSM-III-R schizophrenia N = 63	Social skills training	Discussion group	RCT 36 sessions of 75 minutes, over 18 weeks 9 booster sessions at increasing intervals over 6 month follow-up period BPRS, GAS, SSIT, SCOR, TD, QLS, SANS	Lack of evidence about effects of SST on negative symptoms. Study aims to provide empirical data.	SST produced significantly greater improvements in social skills (assessed in training setting) than control condition. No other significant differences between conditions. Non significant reduction on SANS for SST group. Hypothesis that SST would produce significantly greater improvement in community functioning and clinical status not supported. Neither group changed significantly re time spent in social interaction, participation in activities, self perception of social difficulty (community setting).

2. Cognitive behavioural therapy

Author	Diagnostic criteria/sample	Experimental intervention	Control condition	Design, duration, outcome measures	Rationale for intervention/study aims	Main findings
Klingberg <i>et al.</i> 2009	DSM-IV schizophrenia N = 198	Cognitive behavioural therapy	Cognitive Remediation	Parallel group design 20 sessions of 50 minutes over 9	Study aiming to provide evidence regarding objections to using CBT for negative symptoms (e.g. not feasible because of cognitive deficits,	Study ongoing so still no data re primary outcome of efficacy of CBT v CRT. Evidence that CBT is feasible for

				months PANSS	safety issues due to overstimulation and added stress).	outpatients with negative symptoms. Better participation in CBT than CRT, although worse adherence to agenda and cooperation. No significant difference between CBT and CRT regarding safety parameters.
Perivoliotis & Cather, 2009	Schizophrenia N = 1	Cognitive behavioural therapy	No control	Case study Weekly sessions over course of 1 year SAPS, SANS, DAS, RSAS, GAF	Paper sets out to illustrate the use of innovative methods to tailor CBT for negative symptoms. Provides cognitive case formulation of participant's negative symptoms.	Significant progress (based on engagement in activities, subjective report and observation). SANS pre intervention (severe avolition and apathy, moderate anhedonia and asociality, mild alogia). SANS post intervention (mild avolition and apathy, mild anhedonia and asociality).
Rector <i>et al.</i> 2003	DSM-IV schizophrenia or schizoaffective disorder N = 42	CBT plus enriched treatment as usual (CBT-ETAU)	Enriched treatment as usual (ETAU)	RCT 6 months of weekly sessions (total of 20 sessions) PANSS, BDI	Lack of studies targeting negative symptoms. Examines efficacy of brief CBT.	Both groups improved on positive and negative symptom scales. Trend for greater improvement in negative symptoms in experimental condition. Moderate clinical effect. At 6 month follow up experimental group showed further improvement in negative symptoms, whereas control group worsened=statistically significant group effect.
Johns <i>et al.</i> 2002	DSM-IV schizophrenia or schizoaffective	Group Cognitive behavioural therapy	No	Baseline control design	Study aims to examine whether group CBT would improve negative symptoms, focusing	SANS reduction (non significant) post group for 3 out of 4 participants.

	disorder N = 4			16 group sessions of 1.5- 2 hours, 14 weekly, one after a fortnight and final session one month later. SANS,SENS, CDS, LUNERS	primarily on reduced motivation.	Significant reduction in avolition score for all participants. No significant differences in subjective experience of negative symptoms after group.
3. Integrated therapy						
Author	Diagnosis/sample	Experimental intervention	Control condition	Design, duration, outcome measures	Rationale for intervention/study aims	Main findings
Daniels,1998	DSM-IV schizophrenia or schizoaffective disorder N = 40	Interactive-Behavioural Training	Waiting list	Randomised treatment outcome study 16 sessions of 50 minutes, twice weekly CGI, QLS,SANS, BAT,GAF PANSS	IBT blends CBT, social skills training and group process strategies and intends to increase motivation for social learning and improve skill acquisition, thereby actively targeting negative symptom reduction.	Non-significant difference in SANS scores post treatment.
Miller & Mason, 2004	First episode schizophrenia or schizoaffective disorder N = 71	Cognitive enhancement therapy	No control	Descriptive Group sessions 5 times a week (inpatients) or once a week (outpatients) No formal measures	CET combines supportive therapy, social skills training and cognitive remediation in an attempt to increase social skills, self esteem and confidence. Pays particular attention to increasing motivation for treatment.	Favourable impressions and patient report in favour of CET. Need for research into effectiveness of CRT and need to differentiate and target symptoms more clearly.

Madianos & Economou, 1988	DSM-III chronic schizophrenia N = 106	Long-term community based intervention	Routine outpatient care	Prospective, longitudinal study Follow up service, multidimensional program over an average of 54 months GAS, FAS, CAS	Aims to prospectively investigate effects of community based aftercare on the course of negative symptoms.	No difference between groups at first and second assessments. At 5 year follow up, significant negative symptom decrease in treatment group at 0.05 level.
Thorup <i>et al.</i> 2005	ICD-10 schizophrenia, acute or transient psychotic disorder, schizotypal, schizoaffective, other delusional disorders in F.2 spectrum N = 547	Integrated treatment	Standard treatment	RCT Weekly individual sessions, Social skills training biweekly for 2 months and weekly for 10 months, Multifamily group sessions for 1.5 hours, bimonthly for 18 months SCAN interviews, SAPS, SANS	Aim to see if IT has an effect on negative symptoms in first episode psychosis.	Negative and positive symptoms reduced following IT in first episode psychosis.
Dyck <i>et al.</i> 2000	DSM-IV schizophrenia or schizoaffective disorder N= 63	Multi-family group psychoeducation	Standard treatment	RCT 3 weekly single family sessions and 1 multiple-family group session, without patients Biweekly multi-family group	Building on earlier studies that applied intervention with acutely psychotic patients.	Significant effect of group treatment on negative symptoms compared with standard care.

				sessions, with patients 12 month period BPRS MSANS		
Herman <i>et al.</i> 2000	Schizophrenia or other psychotic disorders N = 76	Critical Time Intervention (CTI)	Usual Services Only	RCT 9 months of individually tailored support from CTI worker + usual services only for 9 months PANSS	CTI designed to prevent homelessness but speculation that might have an impact on symptoms, especially negative symptoms.	Significant effect of CTI on negative symptoms at 6 month follow up. Modest clinical improvement. Subgroup (P=47) assessed at 18 months – trend towards continued lower levels of negative symptoms in CTI group.
Vauth <i>et al.</i> 2005	DSM-IV schizophrenia N = 138	Computer-assisted cognitive strategy training (CAST) plus vocational rehabilitation And Training of self-management skills for negative symptoms (TSSN) plus vocational rehabilitation	Vocational rehabilitation	RCT 90 minute group sessions twice weekly for 8 weeks PANSS,CDS, SHAPS-D	Negative symptoms have been suggested to limit response to psychosocial intervention. Study therefore targets negative symptoms in an attempt to improve outcome and rehabilitation readiness.	No significant difference of TTSN on negative symptoms.

Note:

BAT: Behavioral Assessment Task

BDI: Beck Depression Inventory

BPRS: Brief Psychiatric Rating Scale
BSI: Brief Symptom Inventory
CAS: Community Adjustment Scale
CAT: Client's Assessment of Treatment Scale
CDS: Calgary Depression Scale
CGI: Clinical Global Impressions scales
DAS: Dysfunctional Attitude Scale
EPS: Simpson-Angus Extrapyramidal Symptom Scale
FAS: Family Adjustment Scale
GAF: Global Assessment of Functioning Scale
GAS: Global Assessment Scale
GTFm: Gießentest observer assessment
GTS: Gießentest self-assessment
HAS: Helping Alliance Scale
HONOS: Health of the Nation Outcome Scales
IIP: Inventory of Interpersonal Problems
LUNERS: Liverpool University Neuroleptic Side Effects Rating Scale
MANSA: Manchester Short assessment of Quality of Life
MSANS: Modified Scale for the Assessment of Negative Symptoms
PANSS: The Positive and Negative Symptom Scale for Schizophrenia
Perc QoL: Lancashire Quality of Life Profile
QLS: Quality of Life Scale
RSAS: Revised Social Anhedonia Scale
SANS: Scale for Assessment of Negative Symptoms
SAPS: Scale for Assessment of Positive Symptoms
SCID: Structured Clinical Interview for DSM-III-R
SCON: Conversation with a Stranger Task
SENS: Subjective Experience of Negative Symptoms Scale
SFS: Social Functioning Scale
SHAPS-D: Snaith-Hamilton Pleasure Scale (German version)
SQOL: Subjective Quality of Life
SSIT: Simulated Social Interaction Test
TD: Time Use Diary

5. Review of papers

5.1 Activity based therapy

The studies reviewed in the category of activity based therapy include a paper presenting case studies of the application of a loving-kindness meditation intervention, and randomised controlled trials (RCT) of: body-oriented psychological therapy, music therapy, art therapy and social skills training. Given the variation in interventions, each will be reviewed separately.

Johnson et al. (2009) discussed the application of loving-kindness meditation (LKM; Salzberg, 1995 cited in Johnson et al., 2009)⁷ with people experiencing persistent negative symptoms of schizophrenia, by presenting three case illustrations. In one case the participant is described to have demonstrated improvements in the domains of asociality, blunted affect and motivation both during treatment and at three month follow-up. However, this participant is described to have undertaken previous training in mindfulness meditation which may have enabled her to practise LKM more successfully than the other two cases, with whom outcome was less successful; the second case is reported to have shown improvements in anhedonia, whilst no effect on negative symptoms was noticed in the third case.

⁷ LKM aims to increase the experience of positive emotions by directing feelings of compassion to both the self and others through discussion, skills teaching and practice of meditative techniques (Johnson et al., 2009).

The paper alludes to the application of LKM to a group of participants, however the number is not provided and only vague group demographic details are reported⁸. The study reports the assessment of symptoms, emotions and psychological recovery at baseline, post treatment and three month follow-up. However, neither details of assessment tools used, nor the results of these assessments, are provided. For these reasons, and given the small sample, it is impossible to evaluate the impact of LKM on negative symptoms. However, the paper makes a contribution to the understanding of psychosocial interventions for negative symptoms by highlighting the importance of the development and research of new psychosocial treatments targeting the negative symptoms of schizophrenia and of the importance of a theoretical rationale for these treatments. The paper also contributes to a growing evidence-base of interventions⁹ that incorporate Eastern philosophical and religious concepts, such as mindfulness, with psychotherapeutic approaches, such as CBT.

A different activity based therapy, body-oriented psychological therapy (BPT) was administered to patients with persistent negative symptoms, by Rohricht and Priebe (2006) in an exploratory RCT. BPT was developed from the assumption that “movement and emotional experiences are biologically and experientially associated”, and employs non-verbal techniques to explore cognitive and emotional awareness in relation to the body (Rohricht & Priebe, 2006, 670). Compared to a

⁸ For example, group members are reported to age between “young adult to middle age” (Johnson et al., 2009).

⁹ For example, Mindfulness-based cognitive therapy (MBCT, Segal et al., 2002), dialectical behaviour therapy (DBT, Linehan, 1993), acceptance and commitment therapy (ACT, Hayes et al., 1999) and Compassion-focused therapy (Gilbert, 2009).

control group who received supportive counselling, the study reported a significant effect of BPT on negative symptom scores both after treatment and at four month follow-up. Significantly more participants in the experimental condition were also found to have a reduction in symptoms of 20% or more¹⁰, although details of the level of significance are not provided for this result. The study is, however, limited by its small sample size (see table 1) and high attrition in the control group, which may have contributed to the improvement shown by the experimental group.

Ulrich et al. (2007) discuss two studies, undertaken in China, that report beneficial effects of music therapy on social functioning and negative symptoms (Tang et al., 1994; Yang et al., 1998). In their RCT, Ulrich et al. (2007) compare music therapy with standard treatment, in an attempt to replicate these effects with a German sample. Their results found no significant effect of music therapy on negative symptoms, although there was a trend for a greater decrease in negative symptom scores in the experimental group. However, the study included participants with a diagnosis under the ICD-10 categories F20-F29 (schizophrenia, schizotypal and delusional disorders; WHO, 2002) and, after completing a sensitivity analysis for the subgroup F20 (schizophrenia), participants in the experimental group were found to have significantly lower negative symptom scores than those in the control group. The study included only 37 participants (27 in the schizophrenia subgroup) and the results are therefore not generalisable to all those with a diagnosis of schizophrenia. There was also no follow-up, and thus the long-term effect of

¹⁰ Rector et al. (2003) proposed that a 20% reduction on symptom scores constitutes clinically significant change.

treatment on the negative symptoms of the schizophrenia subgroup is not known. A specific methodological weakness was that participants expressed an interest in engaging in music therapy before randomisation; however, no placebo activity was included in the control group and consent to participate in a RCT was only gained after randomisation. This increases the possibility that participants may not have been blind to the study's aims.

Richardson et al., (2007) discussed the promise and widespread application of art therapy with adult psychiatric patients, but criticise the evidence base for its methodological shortcomings and limited external validity. They present the results of a RCT investigating the effects of art therapy on people with chronic schizophrenia. As an exploratory study to investigate the feasibility of the intervention, the paper does not specify a primary outcome, nor does it include the specific presence of negative symptoms in its inclusion criteria. However, the study does report the use of the Scale for the Assessment of Negative Symptoms (SANS; Andreasen, 1984) but no specific assessment of positive symptoms, indicating a particular focus on negative symptoms as an outcome and, it was on this measure only that a significant effect of art therapy was evident. Interpretation of this result is, however, complicated by the statistically significant difference between baseline negative symptoms of the two groups¹¹. The study also suffers from a lack of power, a high rate of attrition (with only 44% participants interviewed at six month follow up), a “sub-optimal” level of art therapy intervention due to resource

¹¹ At baseline, the group receiving art therapy had lower negative symptom scores.

constraints¹², and assessors who may not have been completely blind to group allocation¹³. The study therefore provides limited support for the use of art therapy as an effective treatment of negative symptoms.

Two studies investigating the use of social skills training (SST) were reviewed. The first compared the effectiveness of SST with a social milieu support approach (involving structured activities, such as discussion and exercise groups) (Dobson et al., 1995) and reported a significant effect of both interventions on negative symptoms at different points during the trial. The reduction in negative symptoms was more significant in the SST group, although this effect was no longer significant at follow-up; whereas the social milieu treatment group appeared to have less effect on symptoms during treatment, but changes sustained at follow-up. The second paper reviewed found no effect of treatment on negative symptoms (Hayes et al. 1995). Both papers suffer from methodological flaws; whilst Dobson et al. (1995) benefited from low attrition and good treatment attendance, the sample size was very small (N=28) and treatment conditions were not compared with a control group. Hayes et al. (1995), on the other hand, used a larger sample and a discussion group control to investigate the effects of SST, but treatment attendance was variable and attrition high. On balance, neither study can be regarded as providing robust evidence in the evaluation of SST for negative symptoms.

¹² It is suggested that most art therapists working with people with chronic schizophrenia would consider a 12 session intervention unsubstantial (Richardson et al., 2007).

¹³ Assessments involved interviewing participants in a way that may have revealed their group allocation.

5.2 Summary

The diversity of activity based interventions reviewed, makes comparison of their results difficult. None presents conclusive evidence of its effectiveness for the improvement of negative symptoms, due either to its novel and exploratory design, or to methodological weaknesses. Rigorous research into the potential efficacy of these treatments is required.

5.3 Cognitive behavioural therapy

Whilst a great deal of empirical research has demonstrated an effect of cognitive behavioural therapy (CBT) on the negative symptoms of schizophrenia, as demonstrated in a recent meta-analysis by Wykes et al. (2008), only four papers were identified where negative symptoms were the primary target. One reason for this may be due to objections that have been raised against the use of CBT for negative symptoms. It has been suggested that patients suffering from cognitive dysfunction, for example attentional deficits or memory problems, might not benefit from psychological intervention or, worse, be harmed by overstimulation and stress caused by the intervention (Klingberg et al., 2009).

Identifying the need for research investigating the efficacy, feasibility and safety of CBT specifically targeting negative symptoms, Klingberg et al. (2009) reported a prospective RCT currently being conducted (treatment of negative symptoms study, TONES) which compares CBT with cognitive remediation (CR). This ongoing study aims to evaluate CBT in reducing negative symptoms in a sample of 198

patients with schizophrenia, as well as to investigate whether it is feasible and safe to use with this particular subset of patients. Data has not yet been published regarding the effect of the intervention on negative symptoms; however the study reports that CBT was more acceptable to participants than CR, as assessed by participation in sessions, although cooperation and adherence to agenda were assessed as being significantly higher in the CR condition. The assessment of these outcomes appears to have been subjective, however, and must be interpreted cautiously.

This same trial is innovative in its monitoring of safety parameters (such as suicide attempts and severe symptom exacerbation) throughout the study and, in the two year period participants were evaluated, no significant differences between groups were found. This result supports Tarrier et al. (2006) who reported no effects of CBT on suicide behaviour in participants with recent onset schizophrenia. The study provides preliminary evidence that CBT may be a feasible intervention for those suffering from negative symptoms; however, its future results pertaining to effect on negative symptoms should be interpreted carefully because of the trial's use of CR as a control. Although the authors argue that the use of CR as a control has more advantages than disadvantages¹⁴ (due to research demonstrating only a small effect size of CR on negative symptoms (McGurk et al., 2007)), the potential effect of CR on negative symptoms in this trial cannot be ignored.

¹⁴ Klingberg et al. (2009) suggest that the use of CR controls for spontaneous change, the effect of involvement in a research trial, and for therapeutic commitment, however they acknowledge it may have some affect on negative symptoms.

Klingberg et al. (2009) discuss the application of “individual strategies designed specifically to reduce negative symptoms” but do not provide details of these strategies, limiting the possibility of replication. Conversely, Perivoliotis and Cather (2009) report a single case study in which CBT was tailored to target negative symptoms, which include adaptations to overcome difficulties with engagement and cognitive functioning, for example. The participant reported subjective progress in areas of functioning, such as activity level and social contacts, and demonstrated improvements in negative symptom scores post intervention, although the detail of these scores are not provided, nor was any follow-up undertaken. Although these results cannot be generalised, the study provides an in-depth cognitive formulation of the participant’s negative symptoms, a sound rationale for the application of CBT to these symptoms, and a detailed account of innovations to cognitive behavioural techniques tailored to address them, upon which future research could usefully build.

A RCT comparing CBT with enriched treatment-as-usual (ETAU¹⁵) was conducted by Rector et al. (2003) and found that both treatments resulted in significant improvements in negative symptom scores, with a trend for greater change in the CBT group. The CBT group were also reported to show continued improvement in negative symptoms at six month follow-up, whereas the control group worsened, resulting in a statistically significant treatment effect on negative symptoms¹⁶.

¹⁵ ETAU comprised comprehensive case management, including: psychoeducation groups, medication management, help with housing and home-based outreach.

¹⁶ 67% participants in the experimental group demonstrated clinically significant gain (>20% reduction in scores), whilst 31% in control group (Rector et al., 2003).

Whilst the study demonstrated some evidence for the potential effectiveness of CBT for negative symptoms, its small sample size, lack of power and relatively high attrition, limits the external validity of the results.

The results presented in a study by Johns et al. (2002) - the only paper reviewed reporting the use of a group intervention - also suffers from serious methodological shortcomings; whilst negative symptom scores reduced following the intervention, only some reached statistical significance. The sample consisted of four participants, of whom only some completed all symptom measures and there was no long term follow-up. However, participant self-reports indicated improvements, for example in the achievement of behavioural goals and satisfaction with the group, providing further support for the feasibility of cognitive-behavioural interventions for those experiencing negative symptoms.

5.4 Summary

The papers reviewed provide preliminary and tentative evidence for both the feasibility and efficacy of CBT for negative symptoms. More RCTs evaluating the use of CBT based approaches to target negative symptoms are essential to determine treatment efficacy.

5.5 Integrated therapy

Johnson et al. (2009) define integrated therapies as those incorporating multiple treatments, including family therapy, social skills training, CBT, or assertive

community treatment, for example. A trial conducted by Daniels (1998) combined social skills training with cognitive behavioural techniques and group process strategies, to form Interactive-Behavioural Training (IBT). However, the study reported only a nonsignificant decrease in participants' negative symptom scores compared to waiting list controls and is limited by methodological flaws, such as a small sample size, lack of any follow-up and no discussion of statistical methods used to analyse the data. Miller and Mason (2004) also present a group treatment, cognitive enhancement therapy (CET), that builds on social skills training with the addition of cognitive remediation and supportive therapy. But, whilst providing a detailed description of the intervention, no control group or formal measures were used to assess or evaluate symptom change, and it is therefore impossible to evaluate the impact of CET on negative symptoms.

Integrated Therapy (IT) interventions are often long-term, as demonstrated by Madianos and Economou (1988), who attempted a prospective evaluation of a community-based aftercare intervention on the course of negative symptoms. 106 participants were observed over an average period of 54 months and whilst no effect on negative symptoms was found during the intervention, a significant decrease in negative symptoms was noted in the experimental condition at five year follow-up. Whilst the paper suffers from numerous methodological limitations, including lack of formal symptom assessment, no randomisation to condition, and only vague details of the intervention content, it does provide some evidence for the feasibility

of long-term interventions with this population, who might be expected (due to motivational difficulties) to find such approaches unmanageable.

Four RCTs, providing more reliable evidence, have been conducted into different types of IT. Thorup et al. (2005) reported a significant effect of a two year program combining assertive community treatment, social skills training and multi-family groups, on negative symptoms in participants with first episode psychosis, compared with standard treatment. However, assessors of symptoms at follow-up were not blind to participants' condition and may therefore not have rated objectively; furthermore inter-rater reliability was only moderate (intra-class correlation coefficient 0.54). Attrition was high in the study and the two groups were not treated equally in respect to frequency of contact; more contact with the experimental group may have resulted in the possibility that better therapeutic relationships were formed than in the control group. Given the well known association between therapeutic relationships and therapy outcome (Blatt et al., 2010), the results must be interpreted cautiously. Although also limited by high attrition, Dyck et al. (2000) conducted a RCT which employed a more rigorous methodology to investigate the use of a similar treatment, multi-family group psychoeducation, which was also compared to standard treatment. Both groups in this study received the same number of treatment hours and a significant effect of group treatment was reported on negative symptoms.

Herman et al. (2000) investigated the impact of a Critical time intervention (CTI)¹⁷ on psychiatric symptoms, both negative and positive, and reported a significant effect of the intervention on negative symptoms only, at six month follow-up. A subgroup of participants followed up at 18 months also demonstrated a trend towards continued lower levels of negative symptoms in the experimental group when compared to controls.

Finally, Vauth et al. (2005) reporting the results of a methodologically robust RCT¹⁸, in which training of self-management skills for negative symptoms (TSSN) (a cognitive behavioural group therapy) was combined with vocational rehabilitation, found no significant impact of treatment on negative symptom improvement.

5.6 Summary

The studies provide inconsistent evidence as to the effectiveness of IT for negative symptoms and many are methodologically flawed, limiting their validity and clinical value. Positive results are also difficult to interpret due to the incorporation of many elements of treatment in IT, making it difficult to identify which aspect of the intervention was effective in improving negative symptoms.

¹⁷ Critical time intervention was originally designed to improve the continuity of care of those suffering from severe mental illness during the critical transition from inpatient to the community, and with the aim of preventing homelessness (Herman et al., 2000).

¹⁸ Although this study also suffered from high attrition, with 27.5% participants dropping out of the study before completion (Vauth et al., 2005).

6. Methodological limitations of the reviewed literature

6.1 Theoretical rationale

The papers reviewed vary in their conceptualisation of negative symptoms, resulting in a diverse array of treatments, and there is also variation in their inclusion of a theoretical rationale for the interventions discussed. Johnson et al. (2009) present a convincing rationale for the use of LKM for negative symptoms, based on the broaden-and-build theory of positive emotions¹⁹ (Frederickson, 2001 cited in Johnson et al. 2009) and Rohricht and Priebe (2006) hypothesise that, given the non-cognitive nature of certain negative symptoms such as emotional withdrawal and motor retardation, they may respond to non-verbal interventions, including sensory awareness techniques. Dobson et al. (1995) justified social skills training on the basis of their conceptualisation of negative symptoms in terms of skill deficits. However, Ulrich et al. (2007), Richardson et al. (2007), Herman et al. (2000) and Thorup et al. (2005), for example, merely speculate on the appropriateness of their interventions without providing any theoretical model or rationale. This lack of rationale may reflect the confusion that surrounds understanding of the aetiology, conceptualisation and course of negative symptoms.

The papers presenting cognitive behavioural interventions include a more convincing basis for their application, perhaps due to recent developments in the cognitive conceptualisation of negative symptoms. Tarrier (2006) discusses the need

¹⁹ The broaden-and-build theory is based upon the belief that the experience of positive emotions enables people to think and act more flexibly which, in the long-term, increases quality of life by building personal resources, perhaps including those which are lacking in those experiencing negative symptoms, including sociality, motivation and anticipatory pleasure (Johnson et al., 2009).

for the development of “testable models” to explain negative symptoms and Stolar (2004) and Stolar & Grant (2007) present a cognitive model of negative symptoms in which they propose that both primary and secondary negative symptoms may, in part, be caused by cognitive processes that relate to perceived lack of purpose, reward, success or pleasure in performing a behaviour, for example. They suggest that assessment and treatment of negative symptoms should consider and address underlying assumptions, dysfunctional beliefs and automatic thoughts. Based upon this model, Perivoliotis and Cather (2009) provide a cognitive case formulation of a participant’s negative symptoms and a description of CBT tailored to address them. Halari et al. (2009) discuss their finding of an association between negative symptoms and a ruminative coping style, whilst Grant & Beck (2009) report a correlation between defeatist beliefs and negative symptoms. Both papers discuss implications of these findings for the future development of interventions to target negative symptoms of schizophrenia.

6.2 Treatment length, specificity and therapist adherence

Comparison of the interventions reviewed is difficult, not only due to the variation in treatment modality, but also due to the differences in length of treatment, clarity of treatment specificity or manualisation, and variation in measures taken to ensure therapist monitoring and adherence to treatment protocol.

Several papers make reference to the possibility that interventions might have been inadequate in length or session frequency (Daniels, 1998; Richardson et al., 2007;

Dobson et al., 1995) resulting in the possibility that treatment effects would have been greater had interventions been optimal²⁰. Whilst some studies provide details of the treatment delivered or manualisation facilitating future replication (Miller & Mason, 2004; Perivoliotis & Cather, 2009), others provide vague information (Klingberg et al., 2009; Thorup et al., 2005), reducing the credibility of the evidence they provide. Furthermore, Waltz et al. (1993) advocate that psychotherapy outcome studies check therapist competence and their adherence to the specified treatment. Whilst many of the studies reviewed discuss measures to ensure interventions were delivered adequately, for example through session taping (Rector et al., 2003; Hayes et al., 1995; Dyck et al., 2000; Daniels, 1998), others make no reference to measures taken to ensure treatment integrity (Thorup et al., 2005; Johns et al., 2002; Ulrich et al., 2007), and may therefore not reflect a true representation of the intervention they present.

6.3 Variation in diagnostic criteria, stage of illness and symptoms

Good experimental designs should draw participants from a specific, homogeneous group (Barker et al., 2002); however there is a great deal of variation in the participants included in the studies reviewed. Whilst the majority of papers reviewed included participants with a diagnosis of schizophrenia or schizoaffective disorder according to guidelines set out in the DSM, others adopted the broader ICD category “psychotic disorders” (Ulrich et al., 2007; Thorup et al., 2005). Participants also varied in their stage of illness, from those experiencing their first-

²⁰ This is supported by the findings of Madianos & Economou (1988), who found significant changes in negative symptoms only after 5 years.

episode of schizophrenia (Miller and Mason, 2004; Thorup et al, 2005) to those suffering with chronic schizophrenia (Hayes et al., 1995). The studies also varied in their exclusion or inclusion of participants with comorbidities or substance abuse, factors which are likely to impact both on participants' ability to engage with interventions and affect their potential for change.

Baseline negative symptom scores also differed greatly between studies, as did their inclusion criteria relating to levels of positive symptoms also experienced by participants. Rohricht and Priebe (2006), for example, included participants with a baseline Positive and Negative Symptoms Scales (PANSS) subscore 'Negative' ≥ 20 (moderate-severe) and/or one of the Anergia items ≥ 6 (severe), whereas Dyck et al. (2000) included participants with symptom scores rated as "slightly greater than mild" according to the Modified Scale for the Assessment of Negative Symptoms (MSANS). Given the nature of negative symptoms, it could be assumed that higher levels may have exacerbated difficulties of engagement in therapy and this may have significant implications in the interpretation of the studies' results. However, comparison is restricted by the fact that some studies provide no details of baseline negative symptom scores (Johnson et al., 2009; Miller & Mason, 2004; Madianos & Economou, 1988), some assessed symptoms using the PANSS, and others the Scale for the Assessment of Negative Symptoms (SANS) or MSANS.

The need for a distinction between, and measurement of, primary and secondary negative symptoms in treatment research was highlighted by Carpenter et al. as

early as 1985. However, of the studies reviewed, none provides a clear definition of whether it includes both primary and secondary negative symptoms, or whether inclusion was restricted to primary, enduring symptoms, resulting in the possibility that treatment responses may reflect not only the effect of the intervention but also heterogeneity among negative symptoms.

6.4 The impact of antipsychotic medication on treatment outcome

A further complication of the lack of differentiation between primary and secondary negative symptoms in the studies reviewed concerns the potentially confounding impact of medication use. Secondary negative symptoms may result from extrapyramidal side effects of antipsychotic medication and may respond to medication directed at their cause (Moller, 2003). Buchanan (2007) explains that in most studies reporting improvements in negative symptoms following drug treatment, concurrent improvements in positive, depressive or extrapyramidal symptoms have also been observed. Thus, if negative symptoms are a result of positive symptoms, for example, the treatment of positive symptoms with medication during a trial might also impact on negative symptoms, thereby confounding the effect of the psychosocial intervention. Only one paper reviewed, however, assessed for extrapyramidal side effects (Rohricht & Priebe, 2006).

First generation antipsychotics (FGAs) have frequently been demonstrated to have little or no impact on negative symptoms, and whilst second generation antipsychotics (SGAs), such as clozapine, olanzapine and risperidone, have been

suggested to be more efficient at treating negative symptoms, effect sizes have been modest and results inconsistent (Makinen, 2008). Some of the studies reviewed considered the potential impact of different types and patterns of medication on participants, for example, by monitoring medication use throughout their study (Rector et al., 2003; Thorup et al., 2005; Herman et al., 2000). Dobson et al. (1995) included participants taking similar types and levels of medication in order to facilitate comparison of intervention effects, whilst Vauth et al. (2005) and Dyck et al. (2000) stratified groups according to medication status. Whereas, other studies (Daniels, 1998; Klingberg et al. 2009; Miller & Mason, 2004; Ulrich et al. 2007; Richardson et al. 2007) include limited or no discussion of the impact of variation in medication use (type, level or compliance) perhaps due to the assumption of the limited the impact of medication on negative symptoms, and thus it is uncertain whether their results are a function of their intervention, or of different medication use.

6.5 Sample size and attrition

Many of the studies included in this review had small sample sizes, sometimes resulting in their being statistically underpowered (Richardson et al., 2007, for example) and high rates of attrition were also commonly reported. Although a common problem in clinical studies of schizophrenia, attrition is an important factor to consider in the evaluation of interventions for negative symptoms as participant attendance is an indication of the acceptability or feasibility of a treatment. Despite high participant attrition amongst the studies reviewed, several also discuss

participant satisfaction; Rohricht and Priebe (2006) for example, report a significant difference in the number of sessions attended by the experimental and control groups, interpreting the better adherence to treatment in the experimental group as a sign of treatment acceptance.

7. Summary

This paper set out to review systematically and critically the small body of research that has focused on psychosocial interventions specifically targeting the negative symptoms of schizophrenia. The studies reviewed were divided into three broad categories; however, the interventions within those categories were diverse, complicating their comparison. Whilst many of the studies reported a significant positive effect of psychosocial interventions on negative symptoms, methodological shortcomings relating to the conceptualisation, definition and assessment of negative symptoms, variation in baseline symptom levels, small sample sizes and high attrition, limit the value of their results. Nevertheless, many of the studies provide support to the growing body of research that has reported effects of psychosocial interventions on negative symptoms as a secondary outcome. Several studies reviewed present novel and innovative interventions, which not only highlight the need for the development and research of new psychosocial treatments for negative symptoms, but also provide mixed preliminary evidence as regards their efficacy, feasibility and acceptability to those experiencing negative symptoms. Thus, although the current evidence relating to the efficacy of psychosocial interventions is inconclusive, the studies provide considerable support

for the necessity of further, more rigorous, research targeting the negative symptoms of schizophrenia.

8. Recommendations for Future Research

Future research should be undertaken in order to replicate existing studies, as well as to develop and evaluate new psychosocial treatments that specifically target the negative symptoms of schizophrenia. However, in the absence of clear definitions and agreement about the negative symptom construct, such research will be limited. It is therefore fundamental that research continues to investigate issues raised by the NIMH-MATRICES Consensus Statement (Kirkpatrick et al., 2006) such as regards the conceptualisation and heterogeneity of negative symptoms.

If future results are to be interpreted with confidence, trials of sufficient size and statistical power should implement interventions that possess an adequate theoretical rationale, and should be clear in their definitions and inclusion criteria relating to diagnosis and symptoms. The design of future trials should be clear as to whether they discriminate between primary and secondary negative symptoms and should isolate those symptoms targeted by an intervention. In relation to psychopharmacological studies of negative symptoms, Buchanan (2007) highlights the need for a clear definition of targeted symptoms, suggesting inclusion criteria relating to assessment and threshold of symptom levels. Arango et al. (2004) and Montgomery and van Zweiten-Boot (2007) advocate the investigation of primary negative symptom change by including participants with low, absent or stable levels

of positive symptoms, depression and extrapyramidal symptoms, thus eliminating the confounds of potential sources of secondary negative symptoms.

However, whilst the use of such criteria in future psychosocial studies would be helpful in discerning which symptoms respond to which intervention, the integration of such research into practice may pose a challenge to mental health services, which are increasingly moving away from a focus on diagnosis towards more difficulty-led approaches (due to controversies discussed in section 2.2). For example, whilst research should move towards isolating symptoms more specifically and towards clarifying the terminology used to identify them, this may be incompatible with services that aim to adopt service-user led language in order to develop a shared understanding of psychotic experiences and symptoms.

Careful discrimination of symptoms, and reliable assessment of baseline symptom severity and change over time, necessitates adequate assessment tools. Although well-established, the current most widely used tools for negative symptom assessment (SANS and PANSS) rely on subjective ratings and are inadequate for assessing the full range of negative symptoms, as well as being limited in their sensitivity to subtle changes (Buchanan, 2007). Furthermore, neither discriminate between primary and secondary negative symptoms, nor do they distinguish negative symptoms from cognitive or affective symptoms (Moller, 2007). Since

their development over 20 years ago, understanding of negative symptoms has changed and the development of new assessment scales has been advocated.²¹

Although some of the papers reviewed discussed participant satisfaction and comments relating to their experiences of the intervention (Rohricht & Priebe, 2006; Johnson et al., 2009; Johns et al., 2002), no qualitative research has been published exploring such experiences. In conjunction with large scale quantitative studies, research adopting an exploratory, qualitative methodology might also provide valuable information regarding the acceptability of psychosocial interventions to those experiencing negative symptoms.

However, whilst the use of such criteria in future psychosocial studies would be helpful in discerning which symptoms respond to which intervention, the integration of such research into practice may pose a challenge to mental health services, which are increasingly moving away from a focus on diagnosis towards more difficulty-led approaches (due to controversies discussed in section 2.2). For example, whilst research should move towards isolating symptoms more specifically and towards clarifying the terminology used to identify them, this may be incompatible with services that aim to adopt service-user led language in order to develop a shared understanding of psychotic experiences and symptoms.

²¹ This has resulted in the development of scales such as the Motor-Affective-Assessment-Scale (MASS; Treméau et al. (2008). Recent research has also investigated the possibility of using computerised analysis of patients' speech to measure negative symptoms (Cohen et al., 2008).

9. Clinical implications

Despite the limitations of some of the studies reviewed, many provide preliminary evidence suggesting that psychosocial interventions may result in improvements in negative symptoms. This review therefore supports the NICE guidelines' (2010) recommendation that services should consider the use of "arts" therapies (including interventions categorised as "activity-based" in this review) for those experiencing negative symptoms. However, although not recommended by the NICE guidelines (2010), the studies in this review also support the growing evidence base (from studies reporting effects on negative symptoms as a secondary outcome) that suggests CBT may be an effective intervention for negative symptoms. Services should therefore also consider offering CBT to target negative as well as positive symptoms of schizophrenia.

10. Conclusion

The need for effective interventions that target the negative symptoms of schizophrenia is undisputed given their prevalence, disabling impact and association with poor long-term prognosis, as well as their resistance to pharmacological treatment. Historically neglected by research into psychosocial interventions, much of the literature reviewed suggests that such interventions may in fact improve negative symptoms and highlights promising avenues for future research. Such research should be rigorous in design, conduct, analysis and reporting, in order that the identification of adequate interventions for negative symptoms of schizophrenia receives the attention, as a clinical priority, it warrants.

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Chapter Two: Empirical paper

**An investigation of parental caregivers' experiences
and perceptions of their sons' negative symptoms in
early psychosis.**

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**Paper prepared for submission to Psychology and Psychotherapy:
Theory, Research and Practice
(See Appendix J for notes to contributors)**

1. Abstract

Increasingly, families are playing an active and fundamentally important role in the care of relatives with psychosis. This role has been linked consistently to high levels of carer “burden” and it has been suggested that negative symptoms of psychosis may represent the most burdensome stressor. However, there has been a lack of research into both the negative symptoms of psychosis in general (compared with positive symptoms) and into carers’ experiences of managing them. Therefore, Early Intervention Services, which aim to work closely with families of relatives experiencing first-episode psychosis, are limited in what they are able to offer to support families whose relatives experience negative symptoms in early psychosis.

This study used a qualitative methodology, Interpretative Phenomenological Analysis (Smith, 1996), in order to explore the experiences of six parental carers of sons experiencing negative symptoms in early psychosis. Analysis of the data revealed two superordinate themes (“Attempts to hold on to the “old” son” and “The search for clarity”) which, through discussion of several subthemes, explore the parents’ personal lived experience of caring for their sons. The themes are discussed in relation to existing literature, particularly with regards to understanding the parents’ experiences of loss, the impact of their individual appraisal of their situation, and to their confusion with regards to their sons’ symptoms and the terminology used to explain them. Clinical implications and recommendations for future research are also discussed.

2. Introduction

2.1 Terminology

The concept of “schizophrenia”, as a valid and reliable diagnostic entity, has been widely disputed (Bentall et al. 1988; Boyle, 2002; Pilgrim, 1990; Van Os, 2009). Therefore, many mental health services have moved from a focus on diagnosis to more difficulty-led approaches (Wykes et al., 1998), including the use of the umbrella term “psychosis” to describe a wide range of different experiences, often viewed as an exaggeration of, and on the same continuum as, “normal” experience. Consequently, researchers are increasingly focusing on the study of individual symptoms and experiences (Flecknoe & Schuller in Beinart et al., 2009) including “positive” and “negative” symptoms of psychosis.

The term “positive symptoms” of psychosis describes the presence of thoughts and perceptions believed to be “abnormal”, such as hallucinations, delusions and disorganised thought; whereas the term “negative symptoms” is based on the concept of deficit, describing a reduction or absence of behaviours considered to be “normal”. The Diagnostic and Statistical Manual of Mental Disorders (DSM-IV, APA, 1994) uses the term to describe “restrictions in the range and intensity of emotional expression (affective flattening), in the fluency and productivity of thought and speech (alogia) and in the initiation of goal-directed behaviour (avolition)” (APA, 1994, 275). It also includes other negative symptoms, such as the diminished capacity to experience pleasure (anhedonia), and social withdrawal. Negative symptoms of psychosis are often classified as either primary or secondary,

where primary negative symptoms (sometimes referred to as “deficit symptoms”) are believed to represent a core feature of the illness, and secondary negative symptom attributed to other factors, such as unrelieved positive symptoms or the effects of antipsychotic medication (Moller, 2007).

Negative symptoms are largely unresponsive to antipsychotic medication and have been shown to be more stable and enduring than positive symptoms (Kelley et al., 2008). People experiencing negative symptoms have been found to have a poorer long-term prognosis than those with predominantly positive symptoms (Andreasen & Olsen, 1982; Barnes & Liddle, 1990; Tandon & Gredon, 1991), and there is a great deal of evidence that negative symptoms are linked to poor functional outcome (including social, vocational and community functioning) (Breier et al., 1991; Sayers et al., 1996) and quality of life (Katschnig, 2000). Despite this, there has been relatively little research into interventions for negative symptoms of psychosis (compared with the extensive research focusing on positive symptoms) and their treatment has been described as a “vital unmet clinical need” (Velligan & Alphas, 2008, p.20).

2.2 Early Intervention in Psychosis

In terms of treatment of psychosis in general, there has been an international move towards “early intervention” which involves holistic and assertive intervention of psychotic features as soon as they are recognised. This is because longer durations of untreated psychosis (DUP) have been associated with poorer long-term outcomes

in terms of response to treatment and recovery from symptoms (Hollis, 2000). Birchwood and colleagues (1993, 2002) discuss the concept of a “critical period” in the treatment of psychosis, suggesting that intervention is most effective during the first three years. Early Intervention Services (EIS) aim to work with those aged between 14 and 35 who have experienced first episode psychosis, and their families, delivering evidence-based care early in the course of psychotic disorder in order to maximise potential recovery²². Given their fundamental role in the care of service users, services also attempt to involve family members and carers as actively as service users themselves (Burbach et al., 2010).

Whilst some studies have reported that longer DUP is associated with increased severity of positive, but not negative symptoms (Harris et al., 2005; Addington et al., 2004), others, such as Scully et al. (1997) and Edwards et al. (1999) have demonstrated that negative symptoms are also related to long DUP. Given their association with poor social and vocational outcome, it is particularly important that EIS specifically address negative symptoms. However, given the historical lack of research into, and the consequential limited understanding of negative symptoms, and interventions for these, little is currently offered by such services to users and their carers in order to help them manage negative symptoms of psychosis.

²² EIS adopt a biopsychosocial and multidisciplinary approach to treatment, offering a wide range of interventions, including psychological, medical, social and vocational, in order to promote recovery within the critical period (Flecknoe & Schuller in Beinart et al., 2009)

2.3 Carer coping

Families are playing an increasingly active role in looking after relatives with psychosis, with 60-70% of service users returning to live with their families after a first episode (Birchwood & Jackson, 2001) and research has consistently demonstrated the resulting “burden” of the caring role (Birchwood et al. 2002). Caregivers may experience increased worry, economic strain, isolation and stigmatisation and find their own social networks reduced (Birchwood et al., 2002). Many studies have demonstrated that elevated levels of anxiety and depression are linked with caring for young people with psychosis (Tennakoon et al., 2000) and trauma reactions have also been found in carers of those with first-episode psychosis (Barton & Jackson, 2008).

Whilst a great deal of research has focused on the measurement of burden in carers, few studies have explored carers’ experiences using qualitative methods (Wynaden, 2007). One qualitative study (Knudson & Coyle, 2002) explored the experiences of parents of people with schizophrenia and found that it was negative symptoms that represented the most burdensome stressor. Other, quantitative, studies have supported this finding. North et al. (1998) reported that families in a psychoeducation program expressed negative symptoms as their main concern, and a number of others have suggested that negative symptoms result in greater carer burden than do positive symptoms (Fadden et al., 1987; Oldridge & Hughes, 1992; Dyck et al., 1999).

Research has revealed that both carers and service users take an active role in coping with their symptoms (Mueser & Gingerich, 1994), and the coping strategies used by carers of people with psychosis have been identified as a fundamental influence in the experience of carer burden, the course of the illness and response to treatment (Magliano et al., 1995). However, despite this and evidence delineating the disabling and burdensome effects of negative symptoms on carers, there has been little research focusing on how people cope with negative symptoms. Mueser et al. (1997) conducted a study of the strategies used, by patients and their relatives, to cope with negative symptoms and found that both patients, and their relatives, who employed more coping strategies (regardless of the type of strategy) reported being more able to cope with negative symptoms. However, the study adopted a quantitative methodology, allowing only speculation as to how or why the use of different coping strategies improved participants' coping efficacy.

Tennakoon et al. (2000) investigated people's experiences of caring for relatives with first episode psychosis and found that, even at this stage, carers used a range of coping strategies. They reported that carers worried most about negative symptoms, but did not focus specifically on how they coped with these symptoms. Further research, exploring carers' experiences of coping with service users' negative symptoms in the early stages of psychosis, is needed to support these important findings prior to development of much needed interventions to support carers.

2.4 Rationale for study

Due to the lack of, and limitations, of existing research into carers' experiences of caring for relatives' with negative symptoms in early psychosis, this study adopts an exploratory, qualitative methodology: interpretative phenomenological analysis (IPA; Smith, 1996). IPA, a specifically psychological research method, does not attempt to test predetermined hypotheses, but enables the detailed exploration of how participants perceive and make sense of their experiences, through the systematic analysis and interpretation of detailed interview data (Willig, 2001). IPA is influenced by the ideas of phenomenological philosophers such as Husserl, Heidegger, Merleau-Ponty and Sartre, as well as by hermeneutics, the theory of interpretation (Smith, Flowers & Larkin, 2009).

As a phenomenological approach, IPA focuses on individuals' perceptions and examination of their life-world; however, following the hermeneutic tradition, it also recognises the active role of the researcher in the interpretative process (Smith & Osborne, 2003). Thus, IPA enables the researcher to make interpretations about meaning, cognition, affect and action involved in participants' experiences, whilst taking into account the context from which the data is generated. It also allows the researcher to reflect upon their role, their views and interactions with participants, in both the processes of interviewing and data analysis (Reid, Flowers & Larkin, 2005). This methodology was chosen over other qualitative methods (such as grounded theory (Charmaz, 2001) or discourse analysis (Potter & Wetherell, 1987))

due to its attention to participants' cognition and its ability to capture the richness of individual experience, both of which are central concerns of this study.

Given the fundamentally important role of families in the care of people experiencing psychosis, and given the knowledge that negative symptoms are difficult to manage, it is vital that the experiences of carers are understood. Despite awareness within services of the serious impact of negative symptoms both on service users and caregivers, little is known about how best to help either group. This research explores how people make sense of their experience of caring for relatives with negative symptoms during early psychosis, how they cope and their perceptions of service provision. In this way, the study aims to fill a gap in the existing research.

To the author's knowledge, no qualitative research has been conducted that has investigated the way in which carers manage their relative's negative symptoms in early psychosis. This study focused on a sample of carers of people experiencing early psychosis, for less than three years, in order to investigate their perceptions and experiences of negative symptoms and address the following questions:

1. How do carers perceive their relative's negative symptoms in early psychosis?
2. What are carers' experiences of managing these symptoms?
3. What are carers' experiences of services in helping them to cope?

3. Method

3.1 Design

The study adopted a qualitative design, deriving data through the use of semi-structured interviews and analysing it according to the principles of IPA.

3.2 Participants

As IPA is influenced by idiography and thus attempts to examine in detail the experiences and perspectives of particular people (Smith, Flowers & Larkin, 2009), participants were selected purposively in order that interviews would be conducted with those people for whom the research questions were significant (Smith & Osborne, 2003).

Participants were recruited through an Early Intervention Service (EIS). Service users, who had experienced the onset of psychosis within the last three years, including negative symptoms, were identified from a large database of routinely collected service data from the Positive and Negative Symptoms Scale²³ (PANSS; Kay et al. 1987). Those with a score on the PANSS negative subscale greater than that on the positive subscale were selected, and a primary caregiver was identified for each of these individuals. Caregivers who were identified as being related to and living in the same household as the service user, with no involvement in the care of

²³ The PANSS specifically assesses both positive and negative symptoms of schizophrenia as well as general psychopathology. It includes a Positive symptom scale, Negative symptom scale and General Psychopathology scale. The Negative scale includes items that assess for: blunted affect, emotional withdrawal, poor rapport, passive-apathetic social withdrawal, difficulty in abstract thinking, lack of spontaneity & flow of conversation and stereotyped thinking (Kay et al. 1987).

others suffering from severe mental or physical illness and who were fluent English speakers, were invited to participate in the study.

These criteria resulted in the exclusion of approximately 40 service users due to: a lack of available caregiver, a caregiver who did not speak English, due to relapse or their positive symptoms becoming more of a concern than their negative symptoms around the time that interviews were conducted, or due to life events (such as housing problems or caregiver illness) preventing them from participating. Parents, siblings, or other relatives (but not professional caregivers) were invited to participate; however, the final sample included only parental carers. The analysis focuses on a final sample of six caregivers²⁴, four mothers and two fathers, all caring for sons between the ages of 19 and 33 years.

²⁴ Smith (2004) explains that detailed IP analysis is only possible with a small sample and may be conducted with a single case.

Table 1. Demographic details of participants and service users

Participant	Pseudonym	Son's pseudonym	Ethnicity	Son's age	Son's diagnosis	Son's PANSS Positive Scale Score	Son's PANSS Negative Scale Score
A	Dennis	Joe	Black Caribbean	19	Psychosis	11	14
C	Grace	Carl	Black/Black British African	21	Psychosis	9	18
D	Karen	Adam	White British	25	Bipolar Disorder	10	15
E	Victoria	Steve	Black/Black British African	21	Psychosis	9	28
F	Pauline	Joseph	Black/Black British African	33	Paranoid Schizophrenia	9	25
G	John	Andrew	White British	22	Depression with secondary psychotic symptoms	17	32

NOTE:

Participant B was excluded following information revealed during interview that breached inclusion criteria.

The potential range of scores on both the Positive and Negative symptom subscales are 7-49, where 7 = complete absence of symptoms.

3.3 Measures

A semi-structured interview schedule was developed, in order to guide the interview towards gathering data that answered the research questions, allowed participants the opportunity to speak freely about their experiences and enabled them to redefine the topic under investigation (Willig, 2001). The interview schedule consisted of six open-ended and non-directive questions, with possible prompts. The first question asked participants to describe the difficulties they perceived the service user to be

experiencing currently or recently, in order to encourage participants to provide a context to their experiences, and to attempt to ease them into the interview process, before asking more specific questions about their experiences and perceptions of negative symptoms. A pilot interview was conducted and the transcript reviewed with supervisors, in order to ensure that the schedule and interview technique facilitated a comfortable and effective dialogue. The interview schedule was developed and refined as a result of this interview (see appendix G).

3.4 Procedure

Ethical approval was obtained from the University Ethics Committee, a local NHS Research Ethics Committee and the Mental Health Trust Research and Development Unit (see appendix A). Potential participants were given an information sheet and an informed consent sheet (see appendices C and D) by their care coordinators, who asked them to consider whether or not they would like to participate in the study. Care coordinators also gave an information sheet and informed consent sheet to the service user relatives (see appendices E and F). Both potential participants and their relatives were given the opportunity to meet or telephone the researcher to discuss the study before deciding whether or not they wished to participate. Once written informed consent was obtained both from participants and service users, semi-structured interviews were conducted. Interview length averaged 50 minutes and all interviews were conducted in participants' homes. All interviews were digitally recorded with participants' consent.

3.5 Qualitative Data Analysis

IPA requires a verbatim record of participants' accounts and, accordingly, interviews were transcribed word for word, including non-verbal utterances and pauses (Smith, Flowers & Larkin, 2009). Each transcript was then anonymised and analysed, line by line, by noting anything of interest in the participant's meaning, understanding and their specific use of language. These exploratory comments were then analysed to identify emergent themes which reflected both the participant's description and the researcher's interpretation (Smith, Flowers & Larkin, 2009). No attempts were made to test specific hypotheses on the basis of existing research, but themes were allowed to emerge during the process of analysis (Smith, 2004). Emergent themes were then reviewed in order to identify emerging patterns and connections between them and to develop super-ordinate themes. A table of super-ordinate and sub-ordinate themes for each case was created before the next transcript was analysed. Once all transcripts had been analysed individually, patterns, similarities and differences in the themes across all the cases were identified. Themes were selected partly due to their prevalence in the data, but also according to the power, articulacy and immediacy of particular passages within the transcripts (Brocki & Wearden, 2006). Finally, transcripts were revisited in order to ensure that the master themes, and verbatim extracts used to illustrate them, were grounded in the original data, before a master table illustrating themes for the group was created (see appendix I).

IPA acknowledges that the researcher “plays an inescapably significant part” in the process of analysis, and encourages reflexivity and exploration of the researcher’s role in interpreting the data (Biggerstaff & Thompson, 2008, p.221). Whilst reading each transcript, thoughts, observations and reflections were noted in a reflexive diary and attempts were made to “bracket” the researcher’s own values and preconceptions, in order to remain focused on participants’ perceptions and generate interpretations grounded in the data (Elliott et al., 1999). However, given the explicitly interpretative role of the researcher, Elliott et al. (1999) also encourage authors to acknowledge and specify their values and assumptions in order to help readers interpret the data. The main author in this study was a trainee clinical psychologist, on placement with an Early Intervention Service (separate to the service from which participants were recruited) at the time the research was conducted. The phases of data collection and analysis coincided with a period of maternity leave and, the experience of becoming a mother herself, may have shaped the way in which the data was interpreted.

In an attempt to ensure credibility of the data analysis, cross-validation of the interpretation of the data was carried out and a process of triangulation was undertaken, whereby two trainee clinical psychologists, undertaking different research using IPA, completed the first stage of analysis on each others’ transcripts. As advocated by Elliott et al. (1999), the data was also discussed with research supervisors with expertise in IPA, at different stages of the analysis in order to check its credibility.

4. Results

Analysis of the six transcripts revealed two superordinate themes. The first theme, “Attempts to hold on to the “old” son” includes three subthemes and encapsulates the emotions, cognitions and actions involved in the participants’ experiences of caring for sons with negative symptoms. The second superordinate theme, “The search for clarity”, includes four subthemes, and explores the relationships between the participants’ personal lived experience and their understanding of their sons’ situations (see table 2). The two themes draw together the particular concerns of individual participants, whilst also demonstrating the commonalities and differences described within their narratives. The superordinate themes will be explored through discussion of their subthemes and will be illustrated by verbatim extracts.

Table 2. Themes

	Superordinate themes	Subthemes
1	Attempts to hold on to the “old” son	a) The “old” and the “new” personality b) Loss c) Struggle to rescue their son
2	The search for clarity	a) “What is happening to my son?” b) Influence of social and cultural context c) Power and responsibility d) Adjustment

4.1 Superordinate Theme 1. Attempts to hold on to the “old” son

The first theme describes the parents’ engagement in attempts to awaken their “old” sons (perceived as independent, smart and full of potential) from their present empty and lifeless state; a state they hope will be temporary, but dread may be permanent.

4.1.1 Subtheme a) The “old” and the “new” personality

This theme is set within the parents’ understanding of how their sons changed during the process of becoming unwell, with their common depiction of them as two different people – the “old” and the “new” son. Victoria and Karen talk explicitly about the “*old Adam*” (Karen, 2, 22) and the “*old Steve*” (Victoria, 8, 131) and many comments were made by all participants about the service users seeming to have become different people. Karen provides an example of this when she says:

He’s not the same person, definitely not, just his whole nature’s changed (Karen, 1, 11).

The “old” sons appear to have represented the parents’ pride and hopes of them becoming independent and successful adults and, at points in several of the transcripts, there is a sense that the parents are disappointed by their son’s new passivity and lack of assertiveness, as well by their lack of drive and aspiration, as Karen illustrates:

Karen: *You just want him to get back to himself, you know, I want him to be...um...happy, and have some goals that he aint really got at the moment, you know like “where can you see yourself in 10 years?” he’ll just go “dunno”, you know I’d rather him have “yeah I wanna do this, I wanna do that”*

Interviewer: Mmm, what does it feel like for you when you think about that?

Karen: *Well it’s just horrible innit cos I want him to have like er ambitions and goals (Karen, 12, 187-192).*

Many of the parents also made comments relating to their “old” son’s intelligence and capabilities and seem perplexed by the “stupid” things they started to say or do, as John’s comment exemplifies:

He says kind of stupid things...but I mean he’s an intelligent boy (John, 23, 374, 383).

The “new” sons are depicted as empty and devoid of personality, exemplified by Grace’s description of her son having “*lost everything*” (Grace, 8, 122). They are also described as being childlike and dependent, requiring support and guidance from their parents in order to carry out every day activities. The following quotations provide examples of how the parents reverted to caring for their sons as they might have done when they were young boys:

***Karen:** He can't do his shoes up now and put his socks on...all his washing's done and you know his bath, his cooking, them kind of things he doesn't do anymore you know somebody does it for him, everything's done for him really (Karen, 17, 278-281).*

***Dennis:** Ryan's a big boy you know what I mean it were kind of funny that his Dad gotta take him somewhere and pick him back up...cos before he didn't need me to do that (Dennis, 21, 458-462).*

4.1.2 Subtheme b) Loss

A sense of loss pervades the accounts of all the parents, at different levels of interpretation. The most tangible accounts relate to the loss of independent skills and adult qualities possessed by the “old” sons, as well as to the loss of other characteristics, such as “*spark*” and “*humour*” (Victoria, 19, 306). Furthermore, the parents’ accounts describe not only the loss of these desirable characteristics as a result of their sons’ negative symptoms, but also of personality characteristics that typified the “old” son, even if these had previously been viewed as unpleasant. For example, in the following extracts, it is as if even these formerly unwanted behaviours were better than the “new” sons’ failure to respond at all, and there is a feeling of nostalgia for past times:

***Karen:** Adam was always in a lot of trouble so I mean, we had a case when the police came to the door, er nothing to do with here, they were just outside and*

they were quite aggressive really, the old Adam would've not have been very happy he'd have just said you know "Do one" but he was just so "yeah alright then well they are allowed..." there was...he he he was so different to how he was, you know like I'm not saying it's a good thing but I dunno he just seems too laid back about a lot of things that normally would've been an issue for him (Karen, 2, 20-25).

Victoria: *he used to be in his room, you know what teenagers are like, listening to his music all night, "turn it down!", I'd rather hear the noise again (Victoria, 14, 235-237).*

More profound examples of loss are also evident in parents' accounts. Their descriptions often give the impression that the "new" sons represent a state of transition between the past (the "old" self) and the future. This state also appears to represent a transitional position between what the parents view as "reality", and a separate, illusory place in which the sons are perceived as being "*miles away*" (Pauline, 16, 253) or in their own "*little world*" (John, 34, 552). Sometimes their parents talked of "*living in hope*" (Victoria, 21, 343) and "*trying to be optimistic*" (John, 29, 470) about their sons' future, viewing the loss of their sons to this state, as a temporary "*rough patch*" (Grace, 28, 466), as the following examples demonstrate:

Grace: *We now see Carl coming back (Grace, 13, 201).*

***Pauline:** I'm just hoping that there's hope at the end you know but he's improved such a lot, because he dropped out of church as well, but now he's started to come back to church (Pauline, 5, 83-84).*

***John:** He has improved he is I think he is, touch wood, he's sort of slowly getting better (John, 3, 38-39).*

However, a deep sense of fear that the future might bring the complete loss of their sons to a permanent state of separation from reality, and from community functioning, permeated the interviews. Pauline, whose son had begun to show improvements in his functioning at the time of interview, recalls this fear:

I felt well, I've lost him really and I didn't know when he was going to recover, you know I didn't know, I prayed and hoped that God would help him but I didn't know that he was going to come round so well as he's done now (Pauline, 17, 270-272).

Karen articulates the pain of her ongoing experience of not knowing whether her son will recover:

Just horrible really because you don't know how long this will last, that's what does your head in, will they get better, will they stay the same? That's, are they

going to get sick again? The worst bit I think's not knowing if they're going to get better, if you're going to see improvements. (Karen, 8, 121-124).

The intensity of feeling that accompanies this fear of complete loss is often evident in the accounts, as illustrated by the following examples, which liken the experience to bereavement:

Victoria: *It's awful. I feel like I'm mourning for the old Steve (Victoria, 8, 131).*

Pauline: *It was very heart rending, I was so distressed, I think it was like a grief that you've lost somebody (Pauline, 9, 138-139).*

Dennis provides a poignant example of a less conscious fear of the permanent loss of his son. He describes his son, Ryan, as a sometimes like a “zombie” (Dennis, 8, 174) and often likens his presentation to a deep state of sleep, or a “daydream” (Dennis, 3, 60). In an attempt to illustrate Ryan’s brief moments of “waking up” (Dennis, 15, 324), he compares him to the people in the film “Awakenings” (an adaptation from the book (Sacks, 1973)), in which patients who have been catatonic for decades having contracted sleeping-sickness briefly “awaken” in response to a new medication. The film concludes with the return of the patients to an assumedly permanent state of catatonia, as the medication fails to achieve its desired effects. Dennis does not discuss the film’s ending, and in fact goes on to explain that his own experience “wasn’t scary or nothing” (Dennis, 9, 189); however, both his use

of this film to illustrate his son's condition, and the urgency with which he denies feeling scared, may be cautiously interpreted as an allusion to a deep fear that the "old" Ryan may, in the future, disappear altogether.

Like Dennis' description of Ryan as a "zombie", Karen uses metaphorical language when she describes her son as "*a vegetable*" (Karen, 7, 106). And, as well as their use of words depicting the loss of their sons to an inanimate or mindless state, many of the parents often used language relating to "up" and "down", giving the impression that the "old" son represented an elevated status of hope, and the "new" son as having fallen to a low position of parental despair. Grace illustrates this when she discusses attempts to "*pull*" her son, Carl, "*up*" (Grace, 12, 192) and contrasts the change in cognitive functioning in the "old" and the "new" Carl when she says:

His way of thinking was high, so he came down (Grace, 21, 342).

John frequently uses similar language to exemplify progression and regression as part of his son's process of recovery:

It's like an up and down thing, we think the trend, the er overall trend we hope and we feel is gradually, but it is very slow, gradually upwards (John, 3, 39-40).

4.1.3 Subtheme c) Struggle to rescue their son

The observation of their sons' regression and fears of the possibility of the total disappearance of the sons they knew – along with the future they had hoped for - appears to have resulted in the parents' engagement in desperate attempts to hold on to or search for ways of rescuing the “old” son. Memories and evidence of how their sons used to be appear to provide motivation for attempts to aid their sons' recovery. Grace explains how she used her son, Carl's, past school reports as proof to others, and perhaps herself, of the existence of the “old” Carl:

He was somebody you know as a child who liked that liked to do things and who was liked amongst his peers...even when he was at nursery school he would take other smaller children, maybe to the toilet and help, you know things like that, he liked going to church, Sunday school...when he was in trouble with the police the other time I took that folder, about his school reports, because I had to tell the social workers, to say “I don't know what is happening to my son” (Grace, 8, 122-135).

Attempts to help their sons involve the parents making personal sacrifices in many areas of their own lives and subjugating their own needs and desires, as the following quotations demonstrate:

***Dennis:** I didn't look out for myself (Dennis, 13, 28)*

Grace: I was even losing my own circles of friends myself, keeping myself to myself (Grace, 17, 276).

Grace: My own private life kept on hold...I've got to make sure that he's alright (Grace, 18, 299-301).

John: I had to just go sort of part time at work (John, 20, 319).

Their accounts also include evidence of the endurance of intense suffering. Use of words such as “*distressing*” (Pauline, 11, 166, 212, 271), “*devastating*” (Grace, 26, 430; Victoria, 11, 177) and “*debilitating*” (John, 20, 322) were frequent. Pauline’s account captures the pain involved in her struggle to try and rescue her son from his symptoms:

It's a burden really, you're burdened and distressed, like your heart is bleeding in your heart really, can't cry outside, but you cry inside cos things haven't worked out the way that you expected it really (Pauline, 10, 153-155).

The parents discuss attempts to use different strategies to encourage their sons’ recovery, often immersing themselves in the caring role. A commonly used strategy involved conversations with their sons, and there was a sense that, whilst they were communicating, they were holding on to a part of the “old” son and, even if only temporarily, preventing the loss of their sons to the “new” state. Dennis provides a

clear example of this, describing engaging in conversation with his son as a way of keeping him temporarily out of his “zombie” state:

Dennis: *constantly talking, constantly talking to him you know what I mean?*

Interviewer: What kind of thing would you talk to him about?

Dennis: *Everything, anything and everything. Constantly, you know what I mean, then it was like he would kind of snap out of it for half an hour (Dennis, 11, 238-241).*

The parents also described attempts to motivate and encourage their sons in efforts to restore them to their “old” selves. The following extracts provide examples of different ways in which they tried to do this and the positive effects of such strategies, even if, as Dennis’ example suggests, they are only temporary:

Dennis: *When he was playing the Wii he was like he can act like he’s normal. Then he finishes playing the Wii and then it’s back again (Dennis, 13, 275-277).*

Karen: *he’s got the baby, take the baby up try to motivate him that way, or sometimes if I’m going out and I’ve got the car I’ll say do you wanna come with me?” (Karen, 12, 194-196).*

John: *we tried to get him to to do things I mean I think physical exercise is important I mean at first he wouldn’t go out at all on his own but now he does go*

out a bit for a walk or a jog, as I say I try to go out on bike rides with him (John, 22, 348-350).

Other efforts to promote their sons' recovery included proactive strategies to reintegrate them into society and encourage them to take on adult roles. Victoria, for example, discussed having "*joined him (Steve) the gym*" (Victoria, 15, 252) and Karen talked about asking Adam's friends to go and see him (Karen, 11 168-171). In attempts to encourage Carl's return to education and future career prospects, Grace took a particularly active role:

Grace: *I must think ahead and probably be financially secure in future in such a way that we can even employ him*

Interviewer: Right

Grace: *So that was my aim now to say "if I do that, if I do that, if I do that" like now with the work I do, I do some freelance work whereby I need a PA, sometimes to record and do the reports, so if he if he knew about IT he would do the reports, you so I was now thinking ahead to say instead of me going back to him to say do this in the meantime you know let me go ahead and sort of equip myself in such a way that I can employ him (...) I've got all these contracts and I can take more contracts if if he can do the reports then I know that I've got a job for him until he wants to go out himself or actually does something (Grace, 27, 446-459).*

The parents also discuss the use of personal coping strategies that, in contrast to their engagement in attempts to rescue their sons from their “new” state, include attempts to avoid and distract themselves from the pain involved in doing so. Grace, for example, talks at length about how she immersed herself in studying and working as a way of coping:

The study helped me cope as well because there was a time I was studying four degrees at one time...I would just bury myself in books thinking...these books are the ones that are going to help me through, so it did help me because I had other things to do...I could audit the 24 hours, what I am doing in the 24 hours, you know take account of everything what am I doing, what am I doing and that sort of helped me to cope (Grace, 22, 367-442).

A sense of movement is evoked by the parents’ descriptions of their fluctuating immersion in attempts to help their sons, and their need for relief and distraction from doing so. This movement in and out of focusing on their sons’ situations echoes their descriptions of the sons’ process of recovery, as they progress and regress, up and down, to and from, the “old” and “new” selves, both minute to minute, as Dennis describes, and over longer periods of time, illustrated by John:

John: *He can have a real sort of like a downer...then in an hour’s time he’ll be looking at something on the computer and he’ll be almost normal, so it’s a bit of an up and down rollercoaster thing (John, 25, 401-404).*

Dennis: He was totally mouth open constantly, dribbling and then he'd look at you and talk and I'd say "Ryan they're talking to you" and he'd wake up and then look at you then he'd drop back again after 5, 10 seconds (Dennis, 12, 257-259).

4.2 Superordinate Theme 2. The search for clarity

The second theme describes socio-cultural influences and processes involved in the parents' attempts to make sense of the confusion and uncertainty that accompanies their sons' negative symptoms, and explores the different stages in their journey towards understanding.

4.2.1 Subtheme a) What is happening to my son?

A strong sense of uncertainty pervaded the parents' accounts of their experiences. One element of this uncertainty concerned their understanding of their sons' condition, expressed clearly by Grace recalling her plea for help from professionals:

"I don't know what is happening to my son" (Grace, 9, 135).

Confusion surrounded many aspects of their sons' presentation, treatment and prognosis. Before beginning the interviews, participants had been given information sheets explaining that the research focused on negative symptoms, and this prompted several comments (unfortunately sometimes before or after the recorded

interviews) relating to confusion about the meaning of the term “negative symptoms”. This issue arose during both John and Victoria’s interviews:

***John:** I’ve heard of negative and positive, I’m a bit confused-you’d think positive would be something good but it isn’t actually (John, 6, 90-91).*

***Victoria:** I’ve been told, but I just don’t understand (Victoria, 5, 75).*

All the parents spoke of their bewilderment in terms of the meaning of their sons’ symptoms and there was a multitude of comments suggesting uncertainty about the causes of their sons’ “*strange behavior*” (Karen, 25, 416). Reflecting on her perceptions of her son’s alogia, Pauline recalls:

I didn’t understand it, I kept saying “why wont you speak up?”, but looking back now I realise now he was ill, he couldn’t manage, he couldn’t, he just couldn’t, he just spoke in a whisper (Pauline, 10, 162-163).

The parents rarely mentioned “psychosis” and often seemed confused about their sons’ psychiatric diagnosis, as the excerpt from Karen’s account implies:

I thought he’d had a break down, um we never ever found out, we’ve never had a diagnosis, the closest diagnosis we had was one doctor said he was bipolar, and I did get paperwork off me own doctor and it did make sense, the symptoms were

so similar it did make sense, and then another one was they said he was psychosis which was psychotic, that half made a bit of sense but it didn't explain the other stuff, I think I was more inclined to believe it was bipolar and I dunno I don't know what's made him like he is now (Karen, 4, 65-70).

Karen's uncertainty about the cause of her son's difficulties is echoed in many of the other accounts, with parents hesitantly mentioning many possible contributing factors, including religious belief, drugs, involvement in criminal activity and genetic factors as well as blaming themselves. Grace encapsulates the uncertainty about the interaction of such factors:

I think he was, um I think he was mentally ill, I wasn't sure whether it was the causal connection was the mental illness, first of all he was just naughty with other children...and then I realised that he was taking cannabis as well, so I don't know whether the cannabis was the causal connection to each of if it's just something that happened through natural occurrence (Grace, 10, 151-153).

The professional treatment offered to the sons also presented as a major source of confusion and uncertainty. The accounts revealed themes relating to lack of clarity about different professional roles and services, and how to access support, as the following example demonstrates:

Victoria: *If I didn't work in the field (within Social Services) I wouldn't know about any of the issues, I wouldn't know what questions to ask, I wouldn't know where to go, who to approach if I needed support or if I need information or if I'm not sure about something, so you know working in the field it's really beneficial to me because there's a lot of people um in the services or family are carers and they don't know anything about mental health, who to go to, what questions to ask (Victoria, 17, 279-283).*

It appeared that the sons' medication was perplexing to the parents, with seemingly unanswered questions arising about why their sons needed medication, which medication they were taking, how long they would need to take it and what effects or side-effects it might have:

Grace: *I think they also changed the medication, and from the time they changed the medication he has been better. Initially he was on another type of medication, I'm not medically trained I don't know what sort of medication it was but maybe he didn't get on well very much with that one (Grace, 6, 87-90).*

John: *he's worried that the medication he's on is um affecting his brain and we don't really know how it works, and we have asked the question and that hasn't really been explained particularly well (John, 3, 50-52).*

A further aspect of uncertainty relating to their sons' illness concerned the future: both in terms of their short and long-term recovery and their prospects and general well-being once their parents were no longer able to care for them. Karen and John reflect this uncertainty and Victoria the anxiety that accompanies it:

Karen: *they just said that things will get better as you go along (Karen, 8, 126).*

John: *we're a bit in unknown, we don't know what to expect (John, 5, 76).*

Victoria: *I worry in case something happens to me what's going to happen to Steve, you know...how would he cope....whoever was caring for him how would they care for him, cos no-one's ever going to do the same level of care that I do, as his mum (Victoria, 9, 147-14).*

4.2.2 Subtheme b) Influence of social and cultural context

It is evident that the parents' individual beliefs, expectations and values, as well as their wider social and cultural context, had a significant impact on the way they perceived, understood and responded to their sons. Pauline frequently referred to her religious faith as an important factor in her understanding and management of her son's difficulties:

One thing that helped me was prayer you know, cos I go to church and I go to prayer meeting and pray and ask God to help, and I've been praying for him and then I think God just changed the situation (Pauline, 13, 212-214).

Karen talked about the influence of her own upbringing on her perceptions of her son's difficulties and care for him, understanding his symptoms as a part of "his way" of being, something that is "meant to be" rather than attributing any causative factors, and thus influencing her coping style of managing them by dealing with "whatever comes along" (Karen, 6, 94-95).

***Karen:** I think that's why I just get on with it because you can't blame the past for how you decide to live your life, you can't you know sometimes it's it's circumstances don't help things but make the most of each situation no matter how bad it is, life goes on you know, we only get life once it's not a rehearsal so I think you've just gotta make the most of it haven't ya, and you know I'm family motivated so whether he was ill or whether he gets back to completely normal and not ill again, you know I will always be the same whichever way they want me, emotionally or physically (Karen, 20, 327-333).*

Many of the participants discussed the difficulty of having to balance their own opinions, judgment and instincts, with the beliefs and advice of others, with whom they often disagreed, about how to help their sons. Dennis, who did not share the same Christian beliefs as his son and some other members of his family and wider

community, describes the difficulty and confusion that resulted from these different belief systems:

His friends, younger kids, religious friends and stuff so you'd say one thing against, not against the religion but, and then they'd say something different...they was trying to help I think but they didn't see that something was directly wrong with him. But they thought God, religion, this, that would get him out of it, but I was trying to explain I spoke to one and I said "just tell him leave the religious thing let's make him do some more things, go cinema whatever this, that" then again he was asking "Dad can I go to this church?" he always goes church almost every day of the week. I think just leave it alone for a while you don't need to go there every week you know what I mean...you have like things like Pastors phoning who want to come down to the house and stuff like that and I'll say "no they aint coming down" you know what I mean, but they think they're helping him with this religion thing but I just think...cos I was just shouting down the phone to them "just leave him alone" (Dennis, 16, 362-380).

At one point everyone had different opinions about his problem and everybody was telling each person telling Ryan how to deal with it and maybe every single person's view on it is different and that confused him...well that's what I found out anyway so I had to have a conversation with everybody else saying "you can't say this and say that and say that" and I'm saying this and you have to be on the same thing even though you don't like it or whatever everyone has to work kinda together (Dennis, 30, 662-664).

Grace provides an example of how, trusting her own judgment and believing in her right as a parent to make decisions about her son's care, caused difficulties for her both within her family and within the wider community:

People who are around you might want to give those ideas so that you know you you adopt that line of thought (belief that son's problems may have come about due to Grace making choices that would displease her dead husband)...So as an African and as a woman you also suffer torture from cultural norms and you have got to think ahead and liberate yourself from that line of thought and say I what I think I know is right yeah and er and this type of problem is acquired because I know that before that he wasn't like that and I know that if his father was here he wouldn't have you know he wouldn't have liked me to suffer the way I am suffering....so I just forged ahead until oh...and the only um person to rely to was social services or any other services because my own, the siblings they would come and take him out but they were not very sure about me reporting anything or being open about it, but then that wasn't the way forward and then I ended up saying "no this is my child I actually gave birth to him, so even though you are also my children but I think I have got a right" (Grace, 18, 283-294).

However, she also talked about helpful social influences on her understanding and management of her situation:

Grace: The other thing that helped me is that cultural you know society here in England, English society you know does not brand women as if you are the wrong doer [...] So I could tell a story, like I am telling you know, and you would, you could also listen “ok that’s not your fault, that’s not your fault” unlike if I was talking to my own people, they are busy building up to say “is it because the father’s not there?” or these are children of single parents or things like that...so society, the way the British society and the way of living as a woman, it made feel stronger because you are also regarded as a person in your own opinion with choices as an individual as opposed to my own culture whereby you are a social misfit if you don’t have a husband you know (Grace, 25, 402-412).

4.2.3 Subtheme c) Power and responsibility

Another area of uncertainty that emerged from the accounts, centred on mixed feelings about who held ultimate responsibility for their sons’ recovery. There was variation of opinion both within individual accounts, perhaps reflecting their confusion about the nature of the symptoms and how to ameliorate them; and also between participants, a result of their individual sociocultural context, beliefs and expectations.

Sometimes the parents exuded a sense of confidence about their rights, responsibilities and ability to help their sons, rather than showing reliance on

professionals or on other members of the family. Many of the parents talked about this overtly:

Dennis: *other members of the family say “he needs help” this, that and I said “nah, he’s alright, I’ll deal with it” they said “he needs help he needs a psychiatrist” (Dennis, 37, 831-833).*

Grace: *it’s now up to me to take him (Grace, 24, 394).*

Pauline: *we don’t get support from relatives, just myself, mainly it was myself really, mostly buy what he needs, what you know, mostly me, mainly me it was mainly me really (Pauline, 25, 413-414).*

John: *I think the most important thing really is us (parents) (John, 30, 495).*

However, at other times they present themselves as helpless and ineffective against the force of their sons’ symptoms. This sense of powerless is clearly illustrated in the following excerpts:

Grace: *Sometimes there was nothing, as a mother, I could do (Grace, 12, 189).*

Victoria: *I just felt helpless that I couldn’t help him...not being able to take everything away and make everything alright for him (Victoria, 8, 133-136).*

Pauline: *I just felt hopeless, like a hopeless situation (Pauline, 17, 274).*

John: *I just felt sort of helpless; I mean what what can you do? (John, 22, 358)*

The accounts also reflected a feeling of the parents' disempowerment by professionals and services, throughout the course of their sons' illness. John epitomises this with his references to being "in their (professionals) hands" (John, 5, 69; John, 30, 486). He also reveals his perception of being less powerful than professionals when, on several different occasions, he discusses experiences of being at the mercy of doctors' decisions:

We wanted to er get him, there's an organisation called (name of voluntary organisation)...and he needed quite a complicated form filling in kind of risk assessment form by the doctor or the psychiatrist, and we we couldn't get this doctor to do it, he kept promising to do it (John, 2, 21-24).

The doctor who's seeing him down at this first place he went on extended leave and we were just sort of left in the lurch, he was on this medication, we didn't know whether we should continue with it (John, 14, 222-224).

This powerlessness, however, appears to have two facets, with parents, on the one hand, appearing angry about the difficulty they had gaining recognition and support

from services when their sons' symptoms first emerged, as excerpts from Grace and Pauline's interviews demonstrate:

Grace: *wherever I was thinking of getting help I couldn't get it but I was so sure there was something wrong with my son (Grace, 3, 46-47).*

Pauline: *I wish the doctor would have listened to me because I've been going to the doctor for years and telling him that Joseph needs help and he wouldn't listen...you just feel as if you're banging your head against a brick wall isn't it because you know you've got a problem and you're talking to somebody and they can't understand (Pauline, 7, 112-121).*

Whilst on the other hand, they appear to be grateful and admiring of the power of professionals to help their sons as the following quotations suggest:

Dennis: *(Ryan) totally broke down until the doctor stopped the whole thing (Dennis, 30, 682).*

Grace: *I think this team helped us a lot, so it's like now the way I feel it's like they gave me my son back (Grace, 31, 507).*

Thus, there appeared from the accounts to be mixed feelings about whether they, the parents, or professionals are best placed to help the sons, with confusion about

where the power and responsibility lies and which group is more effective. There also appears to be some ambivalence about the role of the family and wider community in the care and recovery of the sons, as well as the responsibility of the sons themselves. There are mixed reports about whether other family or community members should be, or are, involved in helping the recovery of the sons, accompanied by an overriding sense that even when others are involved, they do not take responsibility for the sons, exacerbating the parents' sense of being alone in their fight for their sons' recovery.

Various comments were also made, which suggest a perception that, to some extent, the service users are in control of, or perhaps to blame for, their symptoms, and therefore should share some of the responsibility for their own recovery. The following examples illustrate this sentiment that was alluded to by the majority of the participants at some point during their interview:

Dennis: *I thought to myself "how can he..." cos Ryan aint stupid you know what I mean and I think to myself "how did you make yourself turn in to this?" you know what I mean, I kind of say to him "how did that happen Ryan?" you know what I mean "you're not stupid" (Dennis, 13, 293-296).*

Victoria: *Steve's Dad...thinks Steve should just snap out of it...I just want him to try and help himself (Victoria, 10, 168-255).*

John: *we think sometimes perhaps he's afraid, sounds daft, he's afraid of getting better because then he might have more sort of responsibility and have to you know start looking for a job and things like that (John, 26, 427-430).*

The parents' uncertainty about their sons' ability to control their own symptoms is reflected in their comments about having mixed feelings of anger and pity: anger expressed towards their sons as the symptoms presented, and yet pity at their sons' defenselessness against them:

Karen: *I ended up shouting at him and going you know "fuck's sake I'm not going to keep running about blah blah blah" you know me head's thudding and you're going on and I really did go mad at him and then he just went "oh I just wanted to get something to eat mum" and I just thought what a shame, he's so sick (Karen, 7, 111-115).*

Victoria: *Sometimes I shout...then Steve shouts back, or he'll just ignore me and then I'll start feeling guilty for shouting cos I know it's not his fault (Victoria, 24, 399-402).*

John: *we get sort of upset, we've even said to him well think of other people in your family you're you're being selfish, you have to sort of remind yourself that he's ill (John, 18, 285-286).*

This variation in the locus of responsibility appears to be influenced by individual beliefs and expectations, individual sociocultural background, and seems to have had an effect both on the parents' actions and emotions in caring for and coping with their sons' symptoms. For example, Grace describes immigrating to the UK from a country in which she believes she might have been blamed for her son's mental illness and in which he may not have received support from mental health services. This appears to have contributed to her taking ultimate responsibility for the care of her son, resulting in her discussion of caring strategies that emphasise her perseverance, independence, and initiative. Such cultural factors also seem to have influenced her perceptions and evaluation of the services received by her son. For example, at one point she talks about the involvement of a string of different support workers involved with her son due to staff turnover, but evaluates this positively, grateful for all their support (Grace, 4, 67-71). She frequently praises the Early Intervention Service, describing them as "*magical*" (Grace, 31, 513) and a "*team of people who try and deliver outstanding service*" (Grace, 10, 163) and expresses her gratitude when she says:

Thank God we live in a society whereby he gets help (Grace, 30, 503).

Although most of the parents talked of their appreciation of, and gratitude towards, the professionals or services that had helped their sons, those parents that placed greater responsibility with services also appeared to be more likely to criticise them. John, for example, appeared to perceive services as better able to support and help

his son recover than he himself, leading to anger when he felt they had not fulfilled this expectation:

When we saw the doctor he went through like a script and we only got to see him sort of once every once a month at the most, sometimes it was longer than that and he just seemed to say “oh well we’ll try this and this and we’ll try that, what do you think?” sort of thing, well I don’t know you’re the doctor! (John, 15, 232-235).

John also discussed fewer caring and coping strategies than did the other parents, perhaps also reflecting his reliance on services. The variation in the apportionment of responsibility for their sons’ care and recovery may also have impacted on the carers’ experience of burden. Grace, the participant who seemed to take greatest individual responsibility for her son, also made more frequent comments relating to her experience of pressure, burden and difficulty in coping than did other parents; whereas John described the relief that support from services brought him and his wife:

John: *not only does it help Andrew, it helps us, it takes some of the pressure off us, I mean just to be with him all the time is sort of is very stressful (John, 3, 37-38).*

Grace: it takes a lot...it takes a lot (laughs) there was a time when it was only, I don't drink, if was you know, if I drank I would have gone off the rails because it was so much...so much on me, so much in me that...that well...what can you do? (Grace, 30, 494-496).

4.2.4 Subtheme d) Adjustment

The parents described experiencing a variety of emotions in the process of accepting the reality of their sons' symptoms, including intense sadness and depression, guilt and self-blame, anger and frustration. Victoria discusses several of these emotions in the following example:

Victoria: Sometimes I feel angry...like I'm being punished

Interviewer: Can you say more about that?

Victoria: Maybe I blame myself I dunno why but sometimes I you know why didn't I see what was happening, why couldn't I have...you know caught onto the fact that Steve's gone into crisis, I just feel sometimes I should know better, that I missed all the signs and it was in my face (Victoria, 27, 452-456).

Whilst sometimes discussed retrospectively, many of these emotions appeared to continue to impact upon the parents and often surfaced during the interviews. For example, Karen discussed having experienced difficult emotions when her son's symptoms first became apparent, but attempted to describe this experience as something that was in the past and that she had dealt with. However, the continuing

struggle between her cognitive attempts to accept his difficulties and move forward, and her emotional difficulty in doing so, is evident in the following excerpt from her interview:

I just accept that that's his way and that's the way he is, so with Adam I'm quite laid back in that I just accept that what's meant to be, I don't find it a major problem you just deal with you know whatever comes along, you know I'm not one of them people that'd sit there and go oh, I mean I have found it upsetting, when he was first like er well really he'd got no conversation whatsoever, it was awful, to see somebody that's so...loud become...(becomes tearful) see I'm getting upset now, but that was not now that was then (Karen, 6, 94-99).

When talking about the onset of their sons' difficulties, the parents' accounts were often characterised by early attempts to deny the existence of a problem, and included many descriptions of the parents reassuring themselves, and others, that nothing was wrong, but also of their increasing realisation that this was not the case. For example, Grace explains:

I knew at the at the back of my mind that something was wrong, but initially you don't want to believe it and you are refusing to believe it you think ok it's just a rough patch or something (Grace, 21, 342-348).

After a period, at times lengthy, of not recognising the sons' difficulties, the parents often described a specific moment of realisation of a problem. This acknowledgment is frequently reported to occur following a "breakdown" (Dennis, 30, 679), a "peak" in "strange behavior" (Karen, 25, 416), or a "crisis" as Victoria describes:

February, that's when it all...that's when I realised something was wrong...that he was in crisis, but um it was all building up over the past couple of years (Victoria, 2, 31-33).

With this realisation, a process of acceptance appears to be initiated. There are many references to the parents having to accept the changes in their sons and the need to "forge ahead" (Grace, 18, 290) and "just get on with it" (Victoria, 16, 260), coping with "every day as it comes" (Karen, 9, 147); although, the "heaviness" (Grace, 18, 299) and enormity of their sons' difficulties, and the "pressure" (John, 3, 37) and burden placed on the parents as a result, is also evident as the following quotations demonstrate:

Grace: *I had this huge you know problem on me (Grace, 15, 238).*

Victoria: *It's a burden, you're burdened out (Victoria, 32, 531).*

Many of the parents talked about the helpfulness of meeting others in similar situations to themselves, and the relief that accompanied the sharing of their experiences. Pauline talked about her experience of attending a weekend break away with other carers, and explained:

It's quite helpful to know that other people are going through the same things like you know, lots of carers you know, talking to other people as well (Pauline, 6, 87-89).

However, despite this support, or support from friends and relatives, all but one of the participants described feeling isolated and unique in their plight. The following example from Victoria's interview provides a poignant description of this common experience and Karen explains how difficult it is for others to truly understand her experience:

***Karen:** I have friends who's very, very supportive, I did have good friends who are supportive, but I still think that it's very lonely, so no matter how supportive they are, they can't feel what you're feeling, you know they can't, cos they haven't got a clue what's happening in your life, they haven't got a clue, you know it's like "oh what a shame" even little comments they make they mean well and you're thinking "you haven't got a clue what's going on" so you know I don't think that's a lot of help anyway (Karen, 23, 379-384).*

Victoria: I'm feeling a lot more supported, but I still feel as though I'm alone, I'm the only person in the world that's going through it (Victoria, 9, 138).

The process of adjustment to the changed sons also involved changes in relationships and alterations within the wider family system. Several of the parents talked about how they felt closer to their sons as a result of their negative symptoms and the consequential increase in the time spent together, engaging in activities and conversation. However, the sons' difficulties appear to have had a less constructive impact on their siblings, with frequent references being made to how the siblings' lives had been affected and to adverse changes in their relationships with their brothers and parents. An example from Victoria's interview exemplifies the impact of the sons' difficulties on family relationships:

Often everything has to begin round Steve and sometimes I think I pay more attention to Steve than I do his brother...and then his brother will start to act on it, so that's difficult (Victoria, 10, 155-158).

A more positive aspect of the theme of adjustment emerging from the parents' accounts related to learning and making meaning from their experiences. There were references to gaining strength from their experiences, empathy for those in similar situations and insights that might help others. Reflecting on the extent of her learning from the experience of caring for her son, Grace explained:

If I were to write a book I think it would be a very thick book (laughs) about it and it's made me stronger really (Grace, 30, 499-500).

5. Discussion

5.1 Summary of findings

The study set out to explore how a selected group of parents perceived, experienced and managed their sons' negative symptoms in early psychosis. Detailed analysis of the data revealed two superordinate themes. The first theme, "Attempts to hold on to the "old" son" discussed the changes in the sons that were so great their parents perceived them as having become different people. There was a strong sense of fear, and with it, deep emotional pain, that the "old" sons might never be fully recovered; however, the parents appeared to hold on to memories and reminders of what they used to be like in order to motivate their strenuous attempts to encourage their sons' recovery.

The second theme, "The search for clarity", focused on the parents' attempts to understand their sons' experiences and their adjustment to their changing presentations. It explored the involvement of individual socio-cultural context and personal beliefs, expectations and values in their confusion as, not only impacting on their understanding of their sons' symptoms and treatment, such factors also appeared to influence their evaluation of services, as well as the way in which they apportioned responsibility for the implementation of caring and coping strategies intended to help the recovery process. A picture of ambivalence emerged as to who

ultimately held the most power to help, and responsibility for, the sons—their parental carers, other family members, professional services or the service users themselves.

5.2 The perceived impact of negative symptoms in early psychosis

The parents in this study often used metaphorical language, for example depicting their sons as inanimate, to convey their loss. Lakoff and Johnson (1980) suggest that human thought processes, conceptual systems and therefore use of language, are metaphorically structured, thus examination of the parents' use of metaphors may provide an insight into their perceptions of their experiences. The parents' use of orientational metaphors, such as “up and down”, may also be significant, as Lakoff and Johnson (1980) propose such metaphors are rooted in physical and cultural experience, with “up” often used linguistically to depict consciousness, health and life and “down” to represent unconsciousness, sickness and death²⁵. Thus, through their use of language to describe their sons' presentation as a result of their negative symptoms, the parents' fear of the complete loss of the “old” son may be revealed.

This perception of loss is in line with other studies of parents caring for children with severe mental illness. Stein and Wemmerus (2001), Mohr and Regan-Kubinski (2001), Pejler (2001) and Penny et al. (2009)²⁶, for example, all report parental sorrow for the “lost” or changed child. The studies discuss the onset of mental illness resulting in the loss of a “normal life” (Stein & Wemmerus, 2001, 732),

²⁵ Due to the fact that humans stand up when awake but lie down when sleeping, ill or dead.

²⁶ Penny et al (2009) also focused on families of Early Intervention service users.

including loss of skills and abilities, relationships and potential. The parents in the current study also related the loss of their “old” sons to factors such as these, finding themselves resuming a caring role at a time they might have expected their sons to become independent adults. However, due to their sons experiencing high levels of negative symptoms, the parents in this study also discussed the pain involved in witnessing them lose the very characteristics, for example emotional responsiveness, interest, speech and social interaction, that had defined them as people. As such, it may be that this subset of parental carers is particularly vulnerable to experiencing feelings of loss as they not only suffer a symbolic loss of the child they knew and the future they hoped for (like other carers), but also experience a tangible loss in terms of their child’s personality disappearance.

As a result of such perceived loss, several authors have drawn parallels between the reactions of relatives of those suffering from severe mental illness to those of grief (Soloman & Draine, 1996; MacGregor, 1994; Milliken & Northcott, 2003; Rose et al., 2002). Some of the parents in the current study explicitly likened their experiences to grief, and the emotions involved in their adjustment to their changed sons could be likened to those often discussed in relation to bereavement. For example, the parents’ experiences of denial, anger, depression and acceptance are similar to those included in models of grieving and mourning (Kubler-Ross, 1969; Worden, 1991).

Eakes et al.'s (1998) theory of chronic sorrow may also offer a framework within which the parents' responses to their changed sons may be understood. Unlike theories that assert the necessity of resolution as an outcome of the grieving process, the model acknowledges the unique nature of loss that can result from chronic illness, which may be ongoing and have no predictable end, and which therefore prevents closure. It suggests that pervasive, recurrent sadness as well as other feelings characteristic of grief, such as fear, helplessness, anger and frustration, may be experienced as a result of the loss and the disparity it creates between the reality of the individual's situation and what they desire. A cyclical model, it suggests that whilst sadness may subside for periods, people re-experience the feelings first experienced when initially confronted with the loss when situations remind them of this disparity. It may be that in the current study, the parents' descriptions of moving between focusing on and distraction from their sons' situation reflects such a cycle; it may also reflect the oscillation that is central to Stroebe and Schut's (1999) dual process model of coping with bereavement, thus some clinical implications for the assessment and treatment of carers experiencing grief or chronic sorrow are now considered.

A great deal of evidence supports the efficacy of family interventions in early psychosis (Pharoah et al., 2002 cited by French et al., 2010; Pilling et al., 2002), however, Smith and Velliman (2002) suggest that families may be unable to engage in such work if their experiences of loss and mourning are not first addressed adequately. The inclusion of specific grief work as an integral part of family work,

as described by Shannon et al. (1997, cited in French et al., 2010), in their phased approach to working with first-episode families, may be a helpful approach to working with families whose relatives are experiencing negative symptoms in early psychosis. The impact of the sons' negative symptoms on the lives of their siblings was also a theme emerging from the parents' accounts in this study and, whilst only limited research has focused on the impact of first-episode psychosis on siblings, studies have suggested that they too experience grief reactions (Miller et al., 1990; Fisher et al., 2004). Thus the reactions and needs of siblings should also be attended to, as recently advocated by Smith et al. (2010).

5.3 Management of negative symptoms

The grief and sorrow experienced by the parents appears to have been interspersed with periods of optimism and hope, resulting from occasional glimpses of the "old" sons, but periodically re-triggered by events that reminded them of their ongoing caregiving responsibilities. However, it was also through immersion in daily caregiving activities and active attempts to promote their sons' recovery that the parents appear to have coped with their loss. Similar to a finding by Stein and Wemmerus (2001), the parents attempted to find ways to involve their sons in social roles expected of people of their age, for example through social and educational activities. These deliberate efforts to hold on to and encourage the return of the sons they had once known are consistent with findings from other studies that action strategies are often used in order to cope with chronic sorrow, and perhaps help

people to feel more in control (Eakes et al., 1998; Hainsworth et al., 1995; Knudson & Coyle, 2002).

As well as discussing their active attempts to help their sons, the parents described experiencing personal suffering, sacrifice and loneliness. This finding supports extensive evidence of the social and emotional burden that can result from relatives' caring responsibilities for those suffering from psychosis, and the suggestion that negative symptoms may be particularly burdensome (Oldridge & Hughes, 1992; Magliano et al., 2000; Knudson & Coyle, 2002). However, some of the parents in this study also made reference to positive aspects of their caring experiences, thus also supporting the literature that criticises the term "burden" for being too broad and pessimistic (Awad & Voruganti, 2008) and for failing to acknowledge positive aspects of the role of caring for a relative experiencing a psychotic illness (Szmukler, 1996). As a result of these criticisms, Szmukler et al. (1996) instead refer to the "experience of caregiving" (p.138), which may include distress and stigma, but also reward, and attempt to provide a more comprehensive model of caregiving based upon Lazarus and Folkman's (1984) stress-coping paradigm, which suggests that affective and behavioural responses to caregiving are influenced by individual appraisals and that reactions to caregiving may therefore vary over time and context (Szmukler et al., 1996). Others have also discussed the crucial role of carers' appraisal of their situation in influencing how they cope (Barrowclough & Parle, 1997; Scazufca & Kuipers, 1996) and Kuipers et al. (2010) have proposed a cognitive model of caregiving, which suggests that carer appraisals impact on their

cognitive, affective and behavioural reactions towards service users and services as well as carer outcomes²⁷.

The results of the current study support Kuipers et al.'s (2010) model, as parents' appraisals (influenced by their sociocultural context) seemed to affect the way in which they allocated responsibility for their sons' care and recovery. When the responsibility for their son's care was perceived as the parent's own, more active coping and caring strategies were reported, but more burdensome experiences were described. When the locus of responsibility was placed outside the family context (for example, with professionals), fewer caring and coping strategies were described and less burden was reported. This variation in how the parents cared for and coped with their sons has important clinical implications (see section 5.7).

5.4 Experience of services

The Early Psychosis Declaration consensus statement (Bertolote & McGory, 2005) includes family engagement and involvement (including access to information and education) amongst its core values and principles for early intervention with psychosis. However, confusion about psychosis, its treatment (particularly with regards to medication), services and professionals pervaded the parents' accounts.

Such uncertainty has been reported by other studies, for example by Knudson and Coyle (2002), who reported parents' dissatisfaction with the information they were given about their children's illness and treatment by services. Penny et al. (2009)

²⁷ For example, relating to emotional and practical impact on their own lives.

noted the absence of the use of the terms “psychosis” and “schizophrenia” by families in their study, considering the possibility that this might relate to stigmatizing translations and understanding of psychosis within Pakistani culture. However, this finding also emerged from the parents’ accounts in this study and, whilst this may reflect EI services’ tendency to suspend diagnostic decision making in the early stages of psychosis, it may also be suggestive of confusion resulting from insufficient information given to families. Also indicative of the latter proposal, is the parents’ widespread confusion and uncertainty about the meaning of the term “negative symptoms”. Although terminology that is commonly used in clinical practice, and in information given to service users and their carers, there appeared to be an understandable misunderstanding that the term “negative symptoms” referred to symptoms that the parents perceived negatively, as opposed to specific behavioural deficits.

It has been suggested that poor understanding of negative symptoms may result in families attributing symptoms to the character of their relative, rather than to mental illness (Fadden et al, 1987, Hooley et al, 1987), for example, perceiving symptoms as signs of laziness, deliberate avoidance, or irresponsibility (Brewin et al., 1991). Similarly to the findings of other studies (Weisman et al., 1993; Tennakoon et al., 2000), many of the parents in this study suggested their sons were in some way in control of their negative symptoms, and this sometimes appeared to lead to criticism. Family reactions that are critical or hostile (often referred to as “expressed emotion” (EE)), have been widely linked with relapse, and it has been

suggested that the way in which families perceive their relatives' ability to control their symptoms might be an important aspect of the relationship between EE and psychotic relapse (Weisman et al., 1993). High EE has also been strongly correlated with carer burden (Raune et al. 2004). Provencher and Mueser (1997) and Fortune et al. (2005), for example, reported that stronger beliefs that their relatives could control symptoms of psychosis, resulted in greater carer burden and distress in carers.

Carers' understanding of symptoms may also be linked to their thoughts about prognosis and, given the emphasis placed by the Early Psychosis Declaration consensus statement (Bertolote & McGory, 2005) on the importance of generating "optimism and expectations of positive outcomes and recovery", the prevalence of this terminological misconception amongst service users and their families should be further investigated.

5.5 Recommendations for future research

There has been little research investigating the impact of carers' own sense of control over their relative's symptoms and recovery. In this study, the parents' perceptions about the locus of responsibility for their sons' recovery appeared to be an important factor, not only in their experience of burden, but also on coping and caring strategies used, as well as on their evaluation of services. Future research might investigate carers' different attributions relating to responsibility for caring and for the ultimate recovery of service users, as their locus of responsibility may

impact on the way they cope as well as how they respond to service interventions and may thus have important implications for how Early Intervention services best engage and support the needs of different caregivers.

Although unintentional, the participants in this study were all parents of sons and often spoke of their sadness and disappointment relating to their loss of independence and assertiveness; qualities that might be viewed as important elements of the male character amongst British society. One interview (B) was excluded in this study due to the fact that the father interviewed was caring for a daughter with schizophrenia as well as a son experiencing negative symptoms in early psychosis. Whilst the data from his interview was not analysed, the information he provided gave the impression that he may have perceived the impact of negative (and positive) symptoms on his son and daughter differently. Future research exploring the experiences of those caring for daughters with negative symptoms might provide interesting information about the impact of societal expectations of gender roles on caregivers' experiences.

As advocated by Baronet (1999), attention should also be paid to heterogeneity within the carer population²⁸ and to individualised experience, as this may impact on their appraisals. Research focusing on service users' and their families' understanding of the meaning of the terms "negative symptoms" and "psychosis" might also provide helpful insights for services in developing the information and psychoeducation resources to better support service users and their families.

²⁸ For example, exploring the significance of caregiver gender, age, ethnicity and religious beliefs.

5.6 Methodological strengths and limitations

Due to difficulties identifying participants that would meet the study's inclusion criteria, parents were invited to participate if their sons scored more highly on the PANSS negative symptom scale than the positive symptom scale, rather than including only those whose sons' negative symptoms scored above a certain threshold. However, as a result, there was a wide range in the levels of negative symptoms experienced by the sons of parents included in the study.

The interview schedule used in the study was developed by the author and research supervisors. Whilst the schedule was developed and refined following its use during a pilot interview, on reflection, collaboration with service users and their carers in its initial development may have been beneficial. A further limitation of the study relates to the generalisability of its results. Representing the experiences and perceptions of only a small sample of parental carers, the findings must be interpreted cautiously and may not reflect the experiences of others. As IPA involves interpretation, the impact of the researcher's own position in the analysis of the results must also be acknowledged. Despite these limitations, the methodology produced rich narrative accounts, enabling access to insights into the experiences of a specific group of carers that highlight important clinical implications.

5.7 Clinical and service implications

The results of this study suggest that services should be aware of the impact that service users' negative symptoms may have on parental carers. In particular, parents of those experiencing negative symptoms may be vulnerable to feelings of loss and specific grief work should therefore be considered when working with families whose relatives are experiencing negative symptoms in early psychosis.

Kuipers et al. (2010) identified different subgroups of carers and carer/service user relationships (prior to the service user becoming unwell) and explored the influence of these on their reactions to and appraisals of the onset of psychosis. They advocated the need for services to take into account the variation in carer reactions to an episode of psychosis when planning interventions. The results of the current study also highlight the need for services to attend to carer appraisals, as these appeared to influence both the way in which parents cared for and coped with their sons' negative symptoms. If services are to meet the needs of those caring for service users experiencing negative symptoms, attempts should be made to understand individual carers' appraisals of their relative's illness, as well as their perceptions of responsibility for their care and recovery. Attention to such factors, and the way in which they may vary amongst carers, may enable services to engage carers more effectively, facilitate carers own methods of caring and coping, as well as to tailor interventions that better meet the needs of both service users and their carers.

Services should also be aware of the confusion and uncertainty that parents may experience in relation to terminology used to describe and explain service users' symptoms. Attention should be paid to providing comprehensible explanations of the term "negative symptoms" and to using service-user led language in order to adopt a shared understanding of individual experiences.

5.8 Conclusion

Through a detailed exploration of the accounts of a group of parental caregivers, themes emerged relating to their perceptions about the impact of negative symptoms on sons experiencing early psychosis, their own attempts to encourage their sons' recovery, and their efforts to understand and adjust to their sons' altered presentation. Analysis of the themes provided an insight into the experience of caring for those suffering from negative symptoms and, through relating those experiences to existing research, highlighted areas for future research, as well as implications for clinical practice in early intervention for psychosis.

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Chapter Three: Reflective Paper

A reflective review of the research process

Word Count (excluding titles, tables and references): 3,341.

1. Introduction

Schon (1983) introduced the concepts of “reflection in action” and “reflection on action”, and this chapter explores both my reflections during the process of conducting my research and in retrospect, having completed it. It includes considerations of how the research developed, my experiences of the various stages involved in the research process, and reflections on the chosen methodology. It also explores the impact of personal events on the research process, as well as the influence the research had on my learning, not only in relation to research matters, but also to clinical and personal issues.

2. Reflections on the development of interest in Early Intervention in psychosis

During my first assistant psychologist post, I became aware of the work of Early Intervention services, and was struck by the energy and enthusiasm that was common amongst those working in and researching such services. This energy, combined with my existing interest in severe and enduring mental illness and in the use of early, preventative interventions for mental health problems in general, inspired me to learn more about the work of such services and resulted both in my undertaking a placement within an Early Intervention Service, as well as exploring ideas for my thesis in this area.

The idea to conduct research investigating the experiences of those caring for people experiencing negative symptoms of psychosis arose from several meetings

with the Birmingham & Solihull Mental Health Trust Negative Symptoms Group. In the process of investigating the feasibility of this research, I was surprised by the paucity of research in this area, given the significant consequences of negative symptoms to the lives of both service users and their carers. The enormous and pervasive impact that negative symptoms have on carers was illuminated by my involvement in a support and information group for the relatives of Early Intervention service users at the time I was writing my research proposal, encouraging me to pursue this research.

During my literature searches for the empirical paper (chapter two), I became aware that there was a noticeable lack of research into psychological interventions that specifically targeted negative symptoms. I therefore decided to focus my literature review (chapter one) on the research that did exist, as I felt this would be both interesting and clinically useful. I found the initial stages of searching and reading the literature about negative symptoms extremely overwhelming and confusing. On reflection, I think that this was largely due to the lack of clarity regarding terminology and the conceptualisation of negative symptoms that pervades the research. Both the literature review and empirical paper therefore highlight the lack of clarity that exists within research as well as in carers' understanding of negative symptoms, and discuss the implications of this for future research and practice. Whilst collecting my data for the empirical data, many of the participants made comments that related to their confusion about the term "negative symptoms" (see chapter two). However, many of these comments were made in passing, either

before or after digital recording of their interview. I found this frustrating, as I felt these issues were worthy of more detailed analysis, especially given the important implications for clinical practice, due to the widespread use of the term “negative symptoms” with service users and their families.

Given the lack of research, it seemed a qualitative and exploratory approach would best suit the empirical research. After much discussion of the merits, limitations and differences between different qualitative approaches, there was an agreement within the research team that IPA would be the most appropriate methodology to answer the research questions. I was keen to undertake this methodology due to an interest, stemming from my undergraduate degree in Anthropology, in the work of Merleau Ponty, a philosopher influential in the development of IPA, and was excited to revisit phenomenological ideation and to experience its application in research.

With its central focus on examining lived experience, IPA requires the researcher to access the participant’s world. In so doing, the researcher attempts to “bracket” preconceptions, assumptions and judgements (Husserl, 1999, 63 cited in Biggerstaff & Thompson, 2008), often through the use of a reflexive diary. However, it also recognises that such access depends on the researcher’s own ideas and interpretations, and that the “joint reflections of both participant and researcher form the analytic account produced” (Brocki & Wearden, 2006, 88). As reflection plays a fundamental role throughout the process of IPA, the remainder of this paper will

focus mainly on my reflections (from my own reflexive diary) of using this methodology to collect and analyse the data for the empirical paper (chapter two).

3. The experience of conducting the research

3.1 Recruitment

Having spent a great deal of time planning the research, and a long ethics process, I was extremely eager to start interviewing carers. I aimed to interview between 6 and 8 carers and, confident that this was an ample sample size and possible within the time period available, I had not anticipated the difficulties with recruitment and participation that transpired. As IPA requires purposive samples, it was especially important that participants met strict inclusion criteria. However, this immediately reduced the number of potential participants to a very small sample. Having identified participants and gained their consent, I experienced many failed attempts to conduct interviews, due to participants forgetting arrangements or to adverse life events that prevented them from participating. For example, I arrived to interview one participant to find them in the process of moving out having been served an eviction notice. Studies have reported elevated stress, and higher numbers of life events, in the month prior to schizophrenic relapse (Norman & Malla, 1993; Ventura et al., 1989). Thus, whilst frustrating from a research perspective, clinically this was a valuable learning experience in increasing my awareness of the importance of consideration for stressful life events that might be taking place for clients when working with them therapeutically.

3.2 Interview process

In conducting interviews using IPA, Smith et al. (2009) emphasise the importance of establishing a good rapport with participants in order to collect good data. I felt this was especially important in my research as my interview schedule involved asking participants to discuss very personal and emotive issues. Fadden and Birchwood (2002) discuss the difficulties involved in engaging family members of young people with psychosis and Fadden and Smith (2009) talk about the need to establish a positive relationship with families, for example, by expressing genuine concern and listening to their story. In this respect, I found focusing the interviews around an exploration of participants' experiences helpful, and the participants themselves appeared to find the process cathartic. However, having only very little knowledge of the background and circumstances of my participants, and a limited time in which to conduct the interviews, I found establishing a comfortable and trusting relationship so quickly very challenging.

Perhaps in an attempt to compensate for the fact that I felt I had not spent enough time attending to relationship building with participants initially, I sometimes found myself reflecting their feelings or paraphrasing what they had said during interviews, in an effort to make them feel understood. However, whilst this may have been helpful in a clinical setting (Fine & Glasser, 1996) in the IPA context it could be seen as hindering the focus on the examination of participants' lived experience and beginning the process of interpretation too early. Conducting a pilot

interview was very helpful in this respect as it enabled me to reflect on and increase my awareness of such issues before conducting further interviews.

I experienced a feeling of conflict between my role as a clinician, who wanted to communicate empathy and understanding to participants, and as a researcher, who wanted to cover all the research questions and to remain neutral to the participants' responses; thus, I found it difficult to maintain a balance between following the interview schedule, in order to address the questions in which I was interested and, at the same time, remaining attentive to, and exploring, the concerns of participant. This feeling perhaps reflects the unusual position of the IPA researcher in attempting to combine what Smith et al. (2009) describe as "a hermeneutics of empathy with a hermeneutics of 'questioning'", trying to "see what it is like from the participant's view, and stand in their shoes" whilst also standing "alongside the participant, to take a look at them from a different angle, ask questions and puzzle over the things they are saying" (Smith et al., 2009, 36). As I gained more experience in conducting interviews, I found I began to feel more confident in combining these positions and able to use the schedule as a guide, tolerating the uncertainty involved in more spontaneous and participant-led interviews.

3.3 Analysis

Between collecting the data for the empirical paper and writing the thesis, I took a year's maternity leave. I had anticipated difficulties with re-engaging with the data, and conducted one final interview following my leave, which I found enabled me to

reconnect with the previous interviews. What I had not predicted was the significant impact that becoming a mother myself would have on my interpretations of the interview data. The participants often discussed their investment in and nurturance of their sons as they were growing up, as well as the sorrow and disappointment they felt as they watched their sons, and the future they had hoped for, change as a result of their negative symptoms. Such accounts were upsetting to hear both during the interviews and their transcription; however, when I came to analyse the transcripts, following the birth of my own son, I experienced an even deeper sense of empathy when considering how I might feel if I were in their situation in twenty or so years time. Smith et al. (2009) suggest that personal reflections of this nature can aid the process of interpretative analysis, however, I also attempted to maintain awareness of the potential for my preconceptions to hinder the process of analysis and worried that I might be noticing themes that were salient to me, but might not be to others or, more importantly, to the participants themselves. I found it helpful to frequently return to check that the themes I was noticing were grounded in the original data and used tables to chart quotes that supported my themes. I was also reassured by the use of triangulation, during which another trainee independently identified very similar themes (and even similar language to describe them) from one of my transcripts.

As well as identifying the similarities in our interpretations of the data, the process of triangulation also highlighted the scope afforded by IPA for individual creativity in the labelling and conceptualisation of themes. It was this lack of “prescribed”

method (Smith et al. 2009, 79) and encouragement of innovation that I found the most enjoyable aspect of analysing my data. However, for the novice IPA researcher, it was also the most daunting. I found following Smith et al.'s (2009) guidelines for coding the data extremely helpful, but began to feel overwhelmed by the multitude of themes generated. I felt that I could read the transcripts, generate new themes and discover new connections between them endlessly and was uncertain about how I would know when to stop! Having explored and interpreted each transcript in-depth, I found it difficult to reduce the resulting themes, struggling with the impossibility of representing all the concerns expressed by each participant. I felt relieved that I had only six transcripts to analyse (as the early stages of planning the research I had proposed using twelve participants) and was tempted to follow Smith's (2004) encouragement that more IPA studies should focus on the analysis of single cases if they present particularly rich data. I found the interview of one of my participants especially powerful and compelling, and felt a detailed analysis of her transcript could produce ample data for my thesis. However, inexperienced in the methodology and cautious that such an approach might be viewed critically, as well as wanting to discuss interesting themes that had emerged from the accounts of the other participants, I continued with my proposed analysis of a sample of six. If conducting similar research the future, however, I hope that my experience might give me the confidence to conduct more detailed, idiographic exploration of complex human phenomena.

Eventually, I felt ready to organise my themes and identify superordinate themes, and attempted various methods that had been suggested to me by others, including the use of spreadsheets and paper and scissors methods. Ultimately, I discovered the only method of organising the data that made sense to me, which included a large number of tables and diagrams linking them together. During this process I was also encouraged to be more interpretative. Biggerstaff & Thompson (2008) discuss the feeling of discomfort in making such interpretations, commonly experienced by those trained in the use of evidence-based, positivist approaches, and Smith et al. (2009) discuss the tendency of novice researchers to be too cautious and descriptive in their analyses. Supervision, involving the generation of ideas about how themes might be interpreted, was invaluable in helping me to overcome such feelings and in enabling me to move towards more meaningful interpretations of my data and resist the common tendency to be “too easily satisfied with a ‘first-order’ analysis” (Larkin et al., 2006, 103). Supervision also helped me to gauge data “saturation” – a problematic notion in relation IPA, due to the iterative nature of analysis, whereby transcripts are repeatedly analysed as passages from one illuminate themes in others. Brocki and Wearden (2006) suggest that researchers may consider their analysis complete when it “tells a suitably persuasive story”, that is coherent whilst also illustrating nuances in the data (Brocki & Wearden, 2006, 95). However, I found this was something I could determine only in discussion with others.

4. Methodological considerations

Smith (2004) explains that IPA research involves a double hermeneutic, whereby “the researcher is trying to make sense of the participant trying to make sense of their personal and social world” (Smith, 2004, 40). As such, it is inherently subjective, and, like other qualitative methods, this has resulted in questions about its validity and reliability. Yardley (2000) and Elliott et al. (1999) have presented guidelines for assessing the quality of qualitative research within psychology and, in conducting my research, I attempted to address these guidelines in order to enhance the rigour of my research; for example, by grounding themes in examples from my data, and undertaking credibility checks through supervision and triangulation. Elliott et al. (1999) also advocate that authors should acknowledge their own perspectives, due to the fact, as Salmon (2003) explains, that “results of psychological research reflect the researcher as much as the researched” (Salmon, 2003 cited in Brocki & Wearden, 2006, 99). Furthermore, Brocki and Wearden (2006) describe the need for author transparency about factors affecting their own role in interpretation as “a vital facet of IPA” (Brocki & Wearden, 2006, 101). For this reason, in the methodology of my empirical paper, I included disclosure of my own personal experience of becoming a mother, in order to acknowledge the influence of my role in the analysis of the data, for example.

Whilst the role of the researcher in the process of analysis has been well documented, there has been less attention to their role in the process of transcription. Lapadat and Lindsay (1999) discuss the infrequency with which

researchers address theoretical or methodological transcription issues and the common assumption that “transcriptions are transparent, directly reflecting in text the “hard reality” of the actual interaction as captured on audio or videotape” (Lapadat & Lindsay, 1999, 65). In fact, they argue, researchers’ theoretical perspectives impact on the way in which they transcribe their data and this, in turn, has implications for the analysis and interpretations they later draw. They argue that the process of transcription, as a “theory-laden component of qualitative analysis”, should be reflected upon and addressed explicitly in discussions of qualitative methodologies (Lapadat & Lindsay, 1999, 82).

My experience was that the process of transcription was interpretative, and I was aware of making choices about how to represent the data in text. As IPA aims to interpret the content of the participant’s account, Smith et al. (2009) suggest constructing a semantic record of the interview, with other aspects of the interaction with participants included or excluded according to the researcher’s requirements. During the interviews conducted for this study, many of the participants expressed strong emotional reactions whilst recounting their experiences, and I was often aware of the occurrence of transference and countertransference. Following the interviews, I attempted to recall and note these incidences, as I felt these experiences, as well as other non-verbal expressions that took place during the interviews, might have an important bearing on the interpretation of the content of their accounts. However, during the transcription process it was often difficult to bring to mind the nuances of such incidences and therefore to interpret them during

analysis. Although unusual, and introducing potentially ethical and practical complications, if conducting similar research in the future I would consider the use of video recording participant interviews in order that the non-verbal context to the verbal content of participant accounts might be considered as part of the interpretative process.

5. Personal and professional development

As a result of having undertaken this research, I feel I have gained skills and insights both personally and professionally. As my first experience of conducting research with a clinical (as opposed to student) population, I have gained awareness of the challenges of recruitment and engagement of participants and am more conscious of the time and energy required to undertake such research and of how difficult it must be to combine research and clinical practice. However, having gained a much better understanding of IPA (and its applicability to healthcare research) having used it, I hope I will be able to undertake research using the methodology in the future.

The process of undertaking interviews that focus on exploring people's experiences has made me more mindful of the fundamental importance of listening to clients' stories and helping them to feel heard and understood; this is something that I fear I might sometimes rush or take for granted in my clinical practice, due to time or service pressures. Altogether, the research process has highlighted the great need for interventions to help both service users, and their carers, with the problems that

result from negative symptoms of psychosis, and I hope that, one day, this might be an area I could contribute to.

The interaction between my personal experience and that of conducting this research has also been interesting. Reflecting on the completed research, I was surprised by how my personal experiences and perspectives impacted on every aspect of the research process, from selection of a methodology that appealed to my own interests, to the way in which I conducted, transcribed and analysed the interviews. As well as impacting on the research in this way, in turn, it has also impacted upon me. The analysis of the participants' accounts often revealed their thoughts about and experiences of parenting, especially in relation to the hopes and fears that were born with their children; insights which have led me to think carefully about my own experience of having recently become a parent. Thus, in examining the participants' inner world, I have learned more about my own.

6. Conclusion

This chapter has explored reflections that took place during the research process, from conceptualisation to completion, and in retrospect. The challenges and rewards involved throughout the process, and the insights gained, in relation to personal, clinical and research issues have been discussed. I hope to have the opportunity, in the future, to make use of the skills and learning I have gained from my involvement in this research, and to continue to pursue my interest in this area both through further research and in a clinical setting.

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Appendices

Appendix A

08/H1206/42

Page 1



National Research Ethics Service **Birmingham, East, North and Solihull Research Ethics Committee**

REC Offices
Osprey House
Albert Street
Redditch
B97 4DE

Telephone: 01527 587528
Facsimile: 01527 587501

22 May 2008

Miss Imogen Watts
Trainee Clinical Psychologist
Universities of Coventry and Warwick
Clinical Psychology Doctorate
James Starley Building,
Coventry University
Priory Street
Coventry CV1 5FB

Dear Miss Watts

Full title of study: An investigation of carers' experiences and perceptions of negative symptoms in early psychosis.
REC reference number: 08/H1206/42

Thank you for your letter of 14 May 2008, responding to the Committee's request for further information on the above research and submitting revised documentation, subject to the conditions specified below.

The further information was considered by members of a sub-committee of the REC:-

- o Mr R Birkin – Lay member – Acting Vice-Chair;
- o Dr T Priest – Consultant Anaesthetist.

Confirmation of ethical opinion

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

Ethical review of research sites

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

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

This Research Ethics Committee is an advisory committee to West Midlands Strategic Health Authority
The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England

Management permission at NHS sites (“R&D approval”) should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Approved documents

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

<i>Document</i>	<i>Version</i>	<i>Date</i>
Application	5.5	07 March 2008
Investigator CV		07 March 2008
Protocol	1	05 October 2007
Covering Letter		07 March 2008
Peer Review		02 November 2007
Interview Schedules/Topic Guides	1	01 November 2007
Interview Schedules/Topic Guides	2	21 April 2008
Participant Information Sheet: Service User	1	21 April 2008
Participant Information Sheet: Participant	2	21 April 2008
Participant Consent Form: Service User	1	21 April 2008
Participant Consent Form: Participant	2	21 April 2008
Response to Request for Further Information		14 May 2008
Supervisor's CV		07 March 2008
Key Investigator's CV		07 March 2008

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.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document “After ethical review – guidance for researchers” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

08/H1206/42

Please quote this number on all correspondence

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

Yours sincerely


Dr Rex J Polson
Chair

Email: Karen.Green@westmidlands.nhs.uk

Enclosures: "After ethical review – guidance for researchers"

Copy to: Professor Ian Marshall, Coventry University
R&D Office for Birmingham & Solihull Mental Health Trust

Appendix B



Birmingham and Solihull 
Mental Health NHS Trust

R&D Unit, BSMHT
Radclyffe House
66/68 Hagley Road
Edgbaston
Birmingham
B16 8PF
Tel: 0121 678 4326
Fax: 0121 678 4319

Miss Imogen Watts
Trainee Clinical Psychologist
Universities of Coventry and Warwick
Clinical Psychology Doctorate
James Starley Building
Coventry University
Priory Street
Coventry
CV1 5FB

16 June 2008

Dear Miss Watts

Re: "An investigation of carers' experiences and perceptions of negative symptoms in early psychosis."

Thank you for returning your completed Trust Research Application Form for the above project. This research was approved by the Director of Research & Development and we have received notification of a favourable ethical opinion. You may therefore commence the work.

Please note that the Trust's approval of this research is given on the understanding that you are aware of and will fulfil your responsibilities under the Department of Health's *Research Governance Framework for Health and Social Care*, including complying with any monitoring/auditing of research undertaken by the Research & Development Unit.

Please do not hesitate in contacting the Research & Development Unit should you require any advice or support on any aspect of your project. When contacting us it would be helpful to quote our reference number for this project: **NRR 901**.

Yours sincerely

Max Birchwood
Director of Research and Development

Chief Executive: Sue Turner

Appendix C

Coventry University
Priory Street, Coventry CV1 5FB
Telephone 024 7688 8328
Fax 024 7688 8702

Programme Director
Doctorate Course in Clinical Psychology
Professor Delia Cushway
BA (Hons) MSc PhD AFBPS CPsychol (Clin Foren)

THE UNIVERSITY OF
WARWICK



Participant information sheet

Version 2 (21.4.08)

1. Research study title

An investigation into carers' experiences of symptoms of psychosis.

2. Invitation

We would like to invite you to take part in a research study. We carry out research for three main reasons: to find out more about the people who we are trying help; to find out how helpful our services are; and to find out what we should change about the services that we provide.

Before you decide whether you will be able to help us out with our research project, please take the time to read this information sheet. It will explain more about why we are doing this particular research project, and it will tell you about what your participation will involve, if you decide to help us. Please ask us if there is anything you would like us to explain further, or if you would like more information. If you have any questions or would like to meet with the main researcher before deciding whether or not you would like to participate, please contact her on the telephone number provided below. Please discuss your decision with others if you wish. Take time to decide whether or not you wish to take part. This is a research project, and it has no direct link to the standard of care that you and/or your relatives receive.

3. What is the purpose of this study?

Our project aims to gain a greater understanding of the young people and their carers who come into contact with our Early Intervention Service. We are interested in hearing about your opinions and experiences, and would welcome any input that you would be able to give us. By doing this, we hope to be able to improve the services that we provide for young people, and their families.

Dean of Faculty of Health and Life Sciences

Dr Linda Merriman Mphil PhD DpodM CertEd Coventry University Priory Street Coventry CV1 5FB Tel 024 7679 5805

Chair of Department of Psychology

Professor Koen Lamberts BA BSc MSc PhD University of Warwick Coventry CV4 7AL Tel 024 7652 3096

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In particular, we would like to learn more about the needs and concerns of carers coping with symptoms known as “negative” symptoms of psychosis. These include: loss of motivation, social withdrawal, difficulty enjoying activities and problems with memory and attention.

4. Why have I been chosen?

We are hoping to conduct interviews with primary carers of people who attend the Birmingham Early Intervention Service and who are experiencing symptoms known as “negative” symptoms of psychosis.

5. Do I have to take part?

Whether you decide to take part in the study or not is up to you and it will not affect the treatment that you or your relative receive. If you decide to take part, then you will be asked to sign a ‘consent form’ and you will be given a copy of this to keep. This is so that we have a record which shows that we explained the project to you properly, before you agreed to participate. Signing the ‘consent form’ does *not* mean that you cannot change your mind about taking part. Even if you decide to take part, you are still free to withdraw from the project at any time, without giving a reason, and any information you have given would not be used in the study.

6. What will happen to me if I take part?

You will be asked to attend a meeting with a female researcher. The meeting can either be conducted in your home, or at the Early Intervention Service, whichever you prefer. At the meeting, the researcher will ask a few questions to enable you to discuss your experiences and the meeting will last for approximately one hour. There are no right or wrong answers; only your opinion counts. The meeting will be recorded on a digital recorder so that the research team have an accurate record of what is said. Only members of the research team will have access to the recording, and all of the team will sign a ‘confidentiality agreement’ to protect your identity.

After the meeting the research team will study the recording, and they will make detailed notes about what you have told us, using your own words. These notes and recording will be treated confidentially. Your name will not be attached to the recording or the notes and all the information will be kept in a locked cabinet or on a password protected computer. Although we will often use your words, we will not reveal your identity. In all of the reports and documentation for the research project we will refer to you by a false name. We will also be careful to alter or remove any specific information that would identify you. You will be offered the opportunity to see the notes that are made about your meeting and to provide feedback before the final research report is written.

7. What are the possible disadvantages and risks of taking part?

There are no identified disadvantages or risks of taking part on this study. If discussion of the topic becomes difficult, you will be able to stop the meeting at any point if you want to and you will be able to ask any questions once it has finished. Your care coordinator will be informed of your participation in the study and if for any reason you should feel upset by the meeting, they will be able to arrange support for you from the Early Intervention Service.

8. What are the possible benefits of taking part?

There are no intended clinical benefits to participants. However, it is hoped that the information obtained from this study will help to improve the services that are available for service users and carers coping with “negative” symptoms of psychosis.

9. What if something goes wrong?

If you wish to complain, or have any concerns about the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms should be available to you.

10. Will my taking part in this study be kept confidential?

All information collected about you will be kept strictly confidential. However, should you disclose any information during the interview that the researcher believes might put you or another person at risk, the researcher would be obliged to discuss this with your care coordinator.

Any information about you which leaves the Early Intervention Service will have your name removed so that you cannot be recognised from it.

11. What will happen to the results of this study?

The results of this study will be used by the primary researcher, Imogen Watts, as part of the academic requirements of the Coventry and Warwick Doctoral Course in Clinical Psychology. The results of the study will also be put forward for publication in psychology and/or mental health journals. A copy of the results will be made available to all participants, and to the Early Intervention Service. You will not be personally identified in these reports.

12. Who is organising and funding the research?

The study is being organised jointly by Imogen Watts at the Coventry and Warwick Doctoral Course in Clinical Psychology and by Dr Mark Bernard at the Birmingham Early Intervention Service. No payment is being received by any of the organisers for conducting this study.

13. Who has reviewed this study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed by the Coventry University Research Ethics Committee and the National Research Ethics Service.

14. Contacts for further information

We hope that this information is helpful, and reassuring, and that after reading it you feel able to help us with our research. If you have any questions or concerns

about this project, however, please do not hesitate to contact Imogen Watts on **024 7688 7806**. If you have any concerns about this study and wish to contact someone independent, you may telephone Birmingham & Solihull Mental Health NHS Trust Research and Development Unit on **0121 678 4326**.

Thank you for taking the time to read this information.

Appendix D

Coventry University
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Programme Director
Doctorate Course in Clinical Psychology
Professor Della Cushway
BA (Hons) MSc PhD AFBPS CPsychol (Clin Foren)

THE UNIVERSITY OF
WARWICK



Participant consent form

Participant identification code:

Title of study: An investigation into carers' experiences of symptoms of psychosis.

Name of Main Researcher: Imogen Watts

Please initial box

1. I confirm that I have read and understood the information sheet dated 21.4.08 (version 2) for the above study and have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.
3. I consent to the interview being digitally recorded.
4. I agree to take part in the above study

Name of participant

Date

Signature

Name of researcher

Date

Signature

Version 2 (21.4.08)

Dean of Faculty of Health and Life Sciences
Dr Linda Merriman Mphil PhD DpodM CertEd Coventry University Priory Street Coventry CV1 5FB Tel 024 7679 5805

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Appendix E

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THE UNIVERSITY OF
WARWICK



Service user information sheet

Version 1 (21.4.08)

1. Research study title

An investigation into carers' experiences of symptoms of psychosis.

2. Invitation

We would like to invite your carer to take part in a research study. We carry out research for three main reasons: to find out more about the people who we are trying help; to find out how helpful our services are; and to find out what we should change about the services that we provide.

Before you decide whether you will be able to help us out with our research project, please take the time to read this information sheet. Please ask us if there is anything you would like us to explain further, or if you would like more information. If you have any questions or would like to meet with the main researcher before deciding whether or not you would like your carer to participate, please contact her on the telephone number provided below. Please discuss your decision with others if you wish. Take time to decide whether or not you wish to take part. This is a research project, and it has no direct link to the standard of care that you and/or your relatives receive.

3. What is the purpose of this study?

Our project aims to gain a greater understanding of the young people and their carers who come into contact with our Early Intervention Service. We are interested in hearing about your carer's opinions and experiences. By doing this, we hope to be able to improve the services that we provide for young people, and their families.

Dean of Faculty of Health and Life Sciences
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Chair of Department of Psychology
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In particular, we would like to learn more about the needs and concerns of carers coping with symptoms known as “negative” symptoms of psychosis. These include: loss of motivation, social withdrawal, difficulty enjoying activities and problems with memory and attention.

4. Why have I been chosen?

We are hoping to conduct interviews with primary carers of people who attend the Birmingham Early Intervention Service and who are experiencing symptoms known as “negative” symptoms of psychosis.

5. Do I have to take part?

Whether you decide to take part in the study or not is up to you and it will not affect the treatment that you or your relative receive. If you decide to take part, then you will be asked to sign a ‘consent form’ and you will be given a copy of this to keep. This is so that we have a record which shows that we explained the project to you properly, before you agreed to participate. Signing the ‘consent form’ does *not* mean that you cannot change your mind about taking part. Even if you decide to take part, you are still free to withdraw from the project at any time, without giving a reason, and any information you have given would not be used in the study.

6. What will happen to me if I take part?

Your carer will be asked to attend a meeting with a female researcher. The meeting can either be conducted in your home, or at the Early Intervention Service. At the meeting, the researcher will ask your carer a few questions to enable them to discuss their experiences and the meeting will last for approximately one hour. The meeting will be recorded on a digital recorder so that the research team have an accurate record of what is said. Only members of the research team will have access to the recording, and all of the team will sign a ‘confidentiality agreement’ to protect your identity.

After the meeting the research team will study the recording, and they will make detailed notes about what your carer has told us. These notes and recording will be treated confidentially. Your name will not be attached to the recording or the notes and all the information will be kept in a locked cabinet or on a password protected computer. Although we will often use your carer's words, we will not reveal your identity. In all of the reports and documentation for the research project we will refer to you by a false name. We will also be careful to alter or remove any specific information that would identify you.

7. What are the possible disadvantages and risks of taking part?

There are no identified disadvantages or risks of taking part on this study. If discussion of the topic becomes difficult, your carer will be able to stop the meeting at any point and they will be able to ask any questions once it has finished. Your care coordinator will be informed of your carer's participation in the study.

8. What are the possible benefits of taking part?

There are no intended clinical benefits to participants. However, it is hoped that the information obtained from this study will help to improve the services that are available for service users and carers coping with "negative" symptoms of psychosis.

9. What if something goes wrong?

If you wish to complain, or have any concerns about the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms should be available to you.

10. Will my taking part in this study be kept confidential?

All information collected about you will be kept strictly confidential. However, should your carer disclose any information during the interview that the researcher believes might put you or another person at risk, the researcher would be obliged to discuss this with your care coordinator.

Any information about you which leaves the Early Intervention Service will have your name removed so that you cannot be recognised from it.

11. What will happen to the results of this study?

The results of this study will be used by the primary researcher, Imogen Watts, as part of the academic requirements of the Coventry and Warwick Doctoral Course in Clinical Psychology. The results of the study will also be put forward for publication in psychology and/or mental health journals. A copy of the results will be made available to all participants, and to the Early Intervention Service. You will not be personally identified in these reports.

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13. Who has reviewed this study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed by the Coventry University Research Ethics Committee and the National Research Ethics Service.

14. Contacts for further information

We hope that this information is helpful, and reassuring, and that after reading it you feel able to help us with our research. If you have any questions or concerns about this project, however, please do not hesitate to contact Imogen Watts on **024 7688 7806**. If you have any concerns about this study and wish to contact someone independent, you may telephone Birmingham & Solihull Mental Health NHS Trust Research and Development Unit on **0121 678 4326**.

Thank you for taking the time to read this information.

Appendix F

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Programme Director
Doctorate Course in Clinical Psychology
Professor Delia Cushway
BA (Hons) MSc PhD AFBPS CPsychol (Clin Foren)

THE UNIVERSITY OF
WARWICK



Service user consent form

Participant identification code:

Title of study: An investigation into carers' experiences of symptoms of psychosis.

Name of Main Researcher: Imogen Watts

Please initial box

1. I confirm that I have read and understood the information sheet dated 21.4.08 (version 1) for the above study and have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.
3. I agree to my carer taking part in the above study.

Name of service user

Date

Signature

Name of researcher

Date

Signature

Version 1 (21.4.08)

Dean of Faculty of Health and Life Sciences
Dr Linda Merriman Mphil PhD DpodM CertEd Coventry University Priory Street Coventry CV1 5FB Tel 024 7679 5805

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Appendix G

INTERVIEW SCHEDULE

1. Can you tell me what you perceive to be the difficulties the person you care for is experiencing at the moment/or over the last six months?

If mention negative symptoms - explain going to focus on each of these and that will ask some questions about each of these.

If don't-explain particularly interested in negative symptoms - explain what these are and ask if they recognise these/did they in the past?

2. What do you think caused the difficulties they experience?

- How/why do you think they came about?
- Have you had any information about these difficulties?
- Where did the information come from?
- Was it helpful/unhelpful?
- Would anything have been more helpful to you?

3. Can you tell me about what happened the first (most recent) time that occurred?

4. What is it like for you when happens? (ask all questions for each difficulty mentioned)

- How does it affect you?
- In what ways? Positive/ negative
- How does it make you feel?
- How does it affect you in practical terms?
- Does it affect your relationship with x/family life?

5. What do you do (when happens)?

- What helps you to cope?
- What helps x to cope?
- What doesn't help you?
- What doesn't help x?
- Can you tell me about any particular strategies that help you?
- Can you tell me about any particular strategies that help them?
- Can you tell me about their effectiveness?

6. Are there things other people could do to help with the kind of difficulties we've been exploring?

- Services, relatives, friends, service users themselves?
- Are there any people that are helpful or unhelpful to you?
- How?

Appendix H

Example of transcript and coding

1	Interview G (with John father of Andrew)	
2	4.3.10	
3	I: So just to start off really I was just wondering if you could tell me a little bit about some of the	
4	difficulties Andrew's been experiencing, at the moment or over the last few months?	
5	J: Oh he's been <u>poorly</u> for probably...quite a long time but the symptoms came to a head, as it	<i>crisis point - peak in symptoms</i>
6	were, back in when he went to university, er, before last Christmas	
7	I: Uh huh	
8	J: And it was quite bad and we had to go up to uni to er (place) University to um...as a sort of	<i>accidents of mentioning diagnosis</i>
9	rescue mission really and um he seemed to recover a little bit over Christmas and er he went to the	<i>fear of criticism services</i>
10	doctor's and um tried various things, he went to the sort of um the local psychology unit I suppose	<i>active role of parents</i>
11	and er, I've got to be a bit careful what I say but to be frank they weren't particularly good	<i>process of recovery</i>
12	I: right	<i>uncertainty about services</i>
13	J: and we were under the sort of psychiatrist there, saw him perhaps once a month and er Andrew	
14	just during this time getting much worse, er very depressed, er very low, um...just sitting about on	
15	the floor, pacing about, er no interest in anything, lack lack of emotion, that kind of thing um and	
16	added to this was the difficulty we were having with the getting attention for him and also um...I	<i>difficulties accessing help</i>
		1

- desperate
- 17 mean as I say I've got to be careful what I say because we were grateful at that point to get any fear of appearing ingrateful
- 18 sort of help but it became clear he wasn't getting the right help
not wanting to appear ingrateful, but disappointed with service
- 19 I: Right
clear to them - parental intuition
- 20 J: For example, we wanted to get him, there's an organisation called Breakaway, I think it's parental intuition
- 21 part of the Mind, the people called Mind and he needed quite a complicated form filling in kind of
- 22 risk assessment form by the doctor or the psychiatrist, and we couldn't get this doctor to do it, difficulties accessing services
- 23 he kept promising to do it and eventually he told him he'd done it and er I went the next day to
- 24 collect it from his er secretary, when I got there she knew nothing about it, and this was a sort of poor service
- 25 combination of a number of little things and um the woman at the in charge of the centre sort of - getting wrong
- 26 sympathetic and tried to help but she said "well I can't, I don't manage the doctors" so all I did, I never at poor service
- 27 asked her for the complaint number and I didn't know whether I was actually going to make a
- 28 complaint or not and the next day (laughs) this doctor rang me up at work and things really started increase in help following threat to complain.
- 29 to move and that's when we got introduced to the Early Intervention Service, I'd never heard of compensation of service provision
- 30 them, I mean the the level of care and attention of service has been transformed
- 31 I: right, since Early Intervention?
- 32 J: Since they got involved. I mean I'm not saying that Andrew has suddenly got better, he hasn't, improvement since EIS initiated.
- 33 cos it's going to be a really slow job, but we feel now there's like a team of people, I mean improvements will take time but I've suggested
- 2
- slow course of recovery

grateful for holistic support
 - for him & team

34 nobody's perfect, none of us are perfect, but they're looking at the whole person, the medication, the social aspects and they they're sort of getting to know Andrew and he's got a chap who comes and takes him out and takes him to activities and things and it's great, I mean not only does it help Andrew, it helps us, it takes some of the pressure off us, I mean just to be with him all the time is sort of is very stressful, I mean he has improved he is I think he is, touch wood, he's (laughs) sort of slowly getting better, but it's like an up and down thing, we think the trend, the overall trend we hope and we feel is gradually, but it is very slow, gradually upwards

41 I: Um
 42 J: I mean for example he, we, he'll go out on his own a bit now, he he wouldn't have done that say six months ago, he'll go on a bus, this sounds silly, I mean go on a bus? What you on about?

44 But for someone like him that is a major achievement and we, I don't think he would have got that far without the help of the Early Intervention people

46 I: right
 47 J: Um, I mean I don't know whether it, I mean they're all, I mean I go to this carers' group obviously and it's quite a small group, but all the cases are so different, I mean Andrew on the face of it is a relatively mild case actually, some of the people I don't know how they cope I really don't but um, he seems to be um...he's er, he's worried that the medication he's on is um affecting

better than others
 a "case"
 -distancy

3
 comparison with others in similar situation

Cover burden
 Steve is
 fear of deterioration
 upwards / downwards
 seen as different / abnormal
 medication? / distancing
 grateful for holistic support

Appendix I

Master table illustrating themes for the group

1. Loss

In relation to negative symptoms

	Page	Line
A: He was like a zombie	8	174
C: He just lost everything.	8	122
D: All of a sudden you're just looking at him and you think, you're just like a vegetable	7	106
E: He's just withdrawn...he hasn't got that spark anymore, he used to have a sense of humour and that's gone, he doesn't smile	19	306-307
F: He couldn't do anything. Wasn't paying his bills, wasn't reading his letters, wasn't doing the cleaning, wasn't cooking you know washing his clothes properly or nothing like that	1	10-11
G: He's in his own sort of little world	34	552

Loss/return of the "old" self

C: Compare him with his childhood, he just lost everything	8	122
C: I know that before that he wasn't like that	18	288
C: It's like they gave me my son back, because the moment he came back he was different	31	508
D: Such a drastic change from the person they was	4	56-57
D: He's not the same person, definitely not, just his whole nature's changed	1	11
D: I want him to get back to how he was	16	253
E: I know that Steve, that is not Steve	24	397
E: I just have to hope that he comes back	22	358
F: I felt as though I'd lost him really to be honest because I knew what he was like	8	131
F: I felt well, I've lost him really	17	270
F: We thought we just lost him	33	546
G: It's almost as though you're on your own, when he's physically there	19	301

Nostalgia for past times (even if previously viewed as negative)

E: I'd rather be dealing with the autism than what's going on now	3	46-47
E: he used to be in his room, you know what teenagers are like, listening to his music all night, "turn it down!", I'd rather hear the noise again	14	235-237
E: I just miss him hugging me and telling me that he loves me, telling (brother) that he loves him, I just miss it...when he does say it, it's like um, it's almost like he doesn't mean it, there's not that emotion there any more	21	350-352
G: I wish he were interested I wish he'd sort of sort of challenge me about it, it's he's too, I mean he's always been a bit meek and mild	18	294-295
G: be delighted actually if he was! (watching porn)	32	520

Loss of adult qualities, echoes of childhood

A: He's got to work out which way to do something but he can't do it by himself	17	387-388
A: Ryan's a big boy you know what I mean it were kind of funny that his Dad gotta take him somewhere and pick him back up	21	458-460
D: He can't do his shoes up now and put his socks on...all his washing's done and you know his bath, his cooking, them kind of things he doesn't do anymore you know somebody does it for him, everything's done for him really	17	278-281
E: Sometimes I do feel upset to see you know that he's reverted back, I spent so many years helping him to um...you know assert himself or really to build his social skills and I feel like we're just reverting back	27	446-448
F: If he needs to go anywhere I have to go with him	17	278
F: I'll have to go in and teach him some simple things	31	510
G: You forget he's actually	22	82
G: So we could like rotate so that you know there's always somebody with him	20	320
G: He was sort of getting up in the middle of the night and coming into our bed and sitting on the landing in the night and things like that	4	62-64

Psychosis as a transitional state between being here/not being here

A: I don't know if you've seen that film Awakening?... He was like that...Then it was he almost suddenly came out of it almost, it actually was a build up but then one day it was almost	8	180-185
---	---	---------

like it was Ryan again		
A: He was totally mouth open constantly, dribbling and then he'd look at you and talk and I'd say "Ryan they're talking to you" and he'd wake up and then look at you then he'd drop back again after 5, 10 seconds	12	257-259
A: I've never talked to him as much before in my life you know what I mean to keep him awake	27	608-609
A: He was all normal in the day you know just Ryan, as soon as he started praying and it finished that was it, gone, Ryan changed he was like thinking constantly, slouching doing all that kinda stuff that I said before, before he started praying he was normal you know, as soon as he done it he finished	32	708-711
A: At that time he was bit more deep, you know into the problem	36	808
C: I wanted to go and do some volunteering work with people with mental health, so that I would understand, or or and see how they can come back into society	28	462
C: We now see Carl coming back	13	201
C: He picked him up when he was in that state	12	192
F: He would be in a room full of people and he'd still be on his own, you know not communicating, not really a part of it he's still miles away	16	253
G: He's in his own sort of little world	34	552
Fear of total loss		
A: So I got um talking to him and constantly 24 hours a day taking him out with me and trying to wake him up out of it	8	177-178
D: (he'd past tense, as if he's gone, dead?) he might have the odd day where he he comes back dead quick, you know and you think oh that's the old Adam come back... we used to have a laugh before like you know he'd got a funny sense of humour	2	27-29
D: (change in tense-clinging on to "old Adam?) he doesn't interact with people like he used to um I dunno new situations he'd chat, he's like me, quite a gossip, now he'd just sit back and relax	14	217-219
F: I felt well, I've lost him really and I didn't know when he was going to recover, you know I didn't know, I prayed and hoped that God would help him but I didn't know that he was going to come round so well as he's done now	17	270-272
F: I thought he'd lost his mind	21	333
F: Even when my husband said negative things like I don't think he's going to get well, I don't say nothing I just leave it, just keep it to myself really. Not making the situation worse by telling, agreeing with him you know	32	525

Personal loss and sacrifice

(although often difficult to focus on impact on self e.g. D, 8, 130 you just go into robot mode)

A: I can't get to do work...almost nonexistent now	5	103
A: I've come back all the way from wherever I was and that's now frustrating cos I've come back to find out where he's gone and what he's doing if he's in trouble whatever and I come back and he's just down the road but he aint told nobody that he's left and gone anyway	6	118-121
A: I didn't look out for myself	13	28
C: It also really affected me and the way I was living at that time	1	11
C: I was supposed to do the conversion course for about 6 months and then I would go to America but then I couldn't because he was on my papers... but at the same time I could not leave him behind, so when he became, it coincided that he became 18, so I could apply for the citizenship you know without him so that I could pursue the conversion course	5	74-78
C: I was even losing my own circles of friends myself, keeping myself to myself	17	276
C: It was just too heavy for for me to bring anybody in my life even you know to get along with anyone... so my own private life kept on hold actually...because of that and I've got to make sure that he's alright, he's secure	18	299-301
C: I actually suffered a sense of loss because he he was a good person to be with	20	323
C: Although I lost my car, but ... er you know it was for the better ...it was going to cost me him going with the gang or the car	14	228-230
D: We used to have a laugh	2	29
E: Steve doesn't confide in me, or I don't know I don't think he feels comfortable to confide in me... he used to tell me, you know sometimes we'd have a, he'd confide in me but he never does it now	20	331-337
E: I just miss him hugging me and telling me that he loves me, telling (brother) that he loves him, I just miss it...when he does say it, it's like um, it's almost like he doesn't mean it, there's not that emotion there any more	21	350-352
F: I think if I wasn't around I don't think it would have got this better cos I took the time you know to go over there in all weather to see that he was ok	32	527-529
F: At least once a week I was going over and actually buying things that he needs as well, paying his gas bill in the winter	3	48-49
F: Working because I needed to spend my money and to get him sorted out for clothes and things and my husband as well, a lot of our money went into his flat you know	13	204-205

G: I had to just sort of go part time at work 20 319

Loss of hoped for son

As strong

A: I don't think he understands how to control a relationship you know what I mean, not control but to be in one... I think the girls have more control over him 7 151-154

(C: If people can take away your husband of 24 years, anything can happen even in future so I got to an extent whereby I didn't trust anybody...in the sense that I could invest my love in someone, that they would look after me, no I said to myself it has got to be me)? 23 375

D: This is probably a bad example but Adam was always in a lot of trouble so I mean, we had a case when the police came to the door, er nothing to do with here, they were just outside and they were quite aggressive really, the old Adam would've not have been very happy he'd have just said you know "Do one" but he was just so "yeah alright then well they are allowed..." there was...he he he was so different to how he was, you know like I'm not saying it's a good thing but I dunno he just seems too laid back about a lot of things that normally would've been an issue for him 20-25

As intelligent

A: I thought to myself "how can he..." cos Ryan aint stupid you know what I mean and I think to myself "how did you make yourself turn in to this?" you know what I mean, I kind of say to him "how did that happen Ryan?" you know what I mean "you're not stupid" 13 293-296

C: He was very intellectual ...his was of thinking was high, so he came down 21 338-342

C: I'm also surprised by what is happening to my son, to an extent whereby you know he is graded, no he shouldn't be in a formal school with other children. 9 140-141

G: He says kind of stupid things... but I mean he's an intelligent boy 23 374-383

As successful

D, 12, 192 I want him to have like er ambitions and goals 12 192

F: For him to have stayed in work, isn't it you know, smart appearance like he's always had and taking care of himself and you know, not dropped out of church you know 10 157-158

G: I don't know if you've seen that film about Howard Hughes?... I mean he he he was a billionaire... and Andrew got a bit like that actually 10 159-165

G: I think he really believed this he could actually go back in time to when he first went to university and to sort of start again and do it properly 27 437-438

As smart

A: I used to make him look at himself in the mirror...all the time cos I'd say to him "A, you're slouching
15 331-340

you're dribbling, your mouth's wide open" "no I'm not dad, no I'm not" but he's doing it right in front of you there and then, so I took him the first time I took him upstairs in the bedroom and there was a big mirror I said "look in the mirror" then I said "what's wrong with your picture in the mirror?" "I'm leaning to one side dad" so I said "well straighten yourself up then" and then he'd straighten himself up but you could see him leaning back again I said "A..." after 10 seconds he'd be leaning back again I said "A look in the mirror, what's wrong with your picture?" "I'm leaning to the one side again Dad" and he'd straighten himself back up again you know what I mean and I tend to do exercises with him in the mirror cos his body was like a robot, really, really slow

C: Here was a time whereby I thought I would not even ask him to come because of the way he looked 17 270-271

E: Steve loves dressing up in his clothes and he's lost pride in his appearance, he dresses inappropriately for the weather, he'd wear the same clothes all week if he could, you know, he doesn't realise when his clothes are dirty, he's not having a bath 24 393-395

E: I just don't want anyone to be looking at Steve and you know judging him, because of his appearance 26 424

F He used to be very smart and immaculate, he was in the office you see, so he started dressing down...he was unkempt, not dressing well 2 30-32

F: He was scruffy and untidy and I knew that was not like him because he was always immaculate, because I taught him how to wash his own clothes and iron his own clothes and when he was at school he even used to put a seam mark back in his trousers, he was that smart, the teachers used to comment about it as well 19 317-320

F: He's come from changed from what he used to be isn't it, used to be so smart and then he's not smart anymore, his clothes is all shabby, like a tramp 21 330-331

2. Power. Who is responsible?

Parental power/control

- **Over recovery**

	Page	Line
A: I said to myself yeah I'm going to help him get out of it and I had to constantly talk to him about it	9	190-191
A: try and help him, correct him	26	595
A: I used to make him look at himself in the mirror...all the time cos I'd say to him "Ryan, you're slouching, you're dribbling, your mouth's wide open" "no I'm not dad, no I'm not" but he's doing it right in front of you there and then, so I took him the first time I took him upstairs in the bedroom and there was a big mirror I said "look in the mirror" then I said "what's wrong with your picture in the mirror?" "I'm leaning to one side dad" so I said "well straighten yourself up then" and then he'd straighten himself up but you could see him leaning back again I said "Ryan..." after 10 seconds he'd be leaning back again I said "Ryan look in the mirror, what's wrong with your picture?" "I'm leaning to the one side again Dad" and he'd straighten himself back up again you know what I mean and I tend to do exercises with him in the mirror cos his body was like a robot, really, really slow	15	331-340
G: we keep er like a daily log, not in great detail but what he's actually like	4	57-58
F: (Social Services) only doing what they can, that's what they can do cos they've got their clients haven't they so I'll have to go in and teach him some simple things really	31	517-519

- **Over decisions about son's welfare and lifestyle**

A: Just like wasting his money, trying to make him not waste his money like he's getting money now ...but it's managing it...give him the chance to spend he spends every penny in the same day you know what I mean so I have to tell him how to look after his money	25	555-558
C: how am I going to help this child...I've got all these contracts and I can take more contracts if he can do the reports then I know that I've got a job for him until he wants to go out himself or actually does something	28	455-458
C: I ended up saying "no this is my child I actually gave birth to him"	18	293
C: I took the initiative, we used to live in a council flat which was even cheaper, I decided let me come out of here, 3 maybe if we go somewhere where he's not accessible to you know drugs or whatever it might be better	3	49-52
D: you've had to get them sectioned in the first place	25	415

F: At least once a week I was going over and actually buying things that he needs as well, paying his gas bill in the3 48-49
 winter cos he wasn't keeping himself warm either
 F: It didn't affect them (siblings), I didn't burden them with it, I didn't burden them with it or nothing like 32 518-519
 that really

- **Over son's care**

A: other members of the family say "he needs help" this, that and I said "nah, he's alright, I'll deal with it" 37 831-833
 they said "he needs help he needs a psychiatrist"
 C: so it's now up to me to take him 24 393
 C: you keep telling yourself "I've got to make the right decision, I've got to be strong, I've got to do it" 22 352-353
 C: I didn't count on ok I must find somebody else to help me look after the children, I said it has got to be me 23 371-372
 E: no-one's ever going to do the same level of care that I do, as his mum 9 149
 F: Well most of the visits were left to me...you know I think if I wasn't around I don't think it would have got this32 527-529
 better cos I took the time you know to go over there in all weather to see that he was ok
 F: we don't get support from relatives, just myself, mainly it was myself really, mostly buy what he needs, what 25 413-414
 you know, mostly me, mainly me it was mainly me really
 G: we had to go up to uni to er (place) University to um...as a sort of rescue mission really 1 9
 G: I think the most important thing really is us 30 495

- **Over services**

G: I asked her for the complaint number and I didn't know whether I was actually going to make a complaint or 2 26-29
 not and the next day (laughs) this doctor rang me up at work and things really started to move and that's when
 we got introduced to the Early Intervention Service
 G: we saw this notice on on the wall of the the sort of centre about this art psychotherapy... and we didn't really 13 196-200
 know what it was and we made enquiries and we said to the doctor down there do you think he could have this?
 And he said oh yes, yes, yes you know but he hadn't suggested it himself
 G: he went to see the psychiatric nurse and she said, she "assessed" him and said well we don't think he's 15 240-248
 bad enough to see the the psychiatrist doctor he's perfectly alright he can go back to university, I mean that would have been a
 disaster had we let him, we realised that wasn't the case so we insisted he saw the doctor

Parental lack of power/control

- **Over symptoms, behaviour, recovery**

A: He was doing the prayer you could just tell cos he's praying, concentrating hard with his hands together and he's really concentrating like he's got a direct line to God kind of thing and he's really concentrating and you know you've got all your nephews and all that round there who was just realising what was happening and they started giggling and laughing kind of thing and I'd say to him "leave it now" but Ryan's praying so when he was starting it would last 10, 15 minutes but it was going on and on and on and on you know what I mean I was trying to say "don't do it" he kinda went back into his kind of thing.	32	713-719
C: sometimes there was nothing, as a mother, I could do	12	189
C: I didn't know what to do with him	17	268
E: I just felt helpless that I couldn't help him...not being able to take everything away and make everything alright for him	8	133-136
E: I know it's going to take time but I wish it would just hurry up	19	315
F: I just felt hopeless, like a hopeless situation	17	274
G: I just felt sort of helpless I mean what what can you do?	22	358
G: the doctor who's seeing him down at this first place he went on extended leave and we were just sort of left in the lurch, he was on this medication, we didn't know whether we should continue with it	14	222-224

- **Over services**

C: wherever I was thinking of getting help I couldn't get it but I was so sure there was something wrong with my son	3	46-47
C: the first time I noticed the early signs they said there's not a problem	24	398
D: I had days they said he was fine and then I phoned up and he's been really horrible over the phone so I knew he weren't well again and then I find out he's been released and then of course we have another break down cos he wasn't ready	26	428-430
D: when he was in the hospital sometimes you get no information and I think that's when people need support the most, when somebody's first sectioned, cos you've got no idea	22	353-355

E: trying to get that support, it's ridiculous... I've approached Social Services so many times in the past before Steve turned 16 and they were saying he wasn't severe enough or he doesn't meet the criteria... I just feel that there's no support	8	118-122
G: added to this was the difficulty we were having with the getting attention for him	1	16
G: he needed quite a complicated form filling in kind of risk assessment form by the doctor or the psychiatrist, and we we couldn't get this doctor to do it, he kept promising to do it and eventually he told him he'd done it and er I went the next day to collect it from his er secretary, when I got there she knew nothing about it	2	21-24
G: we're obviously we're in their hands	5	69
G: we're sort of in their hands, we we didn't want him to take it this is quite a drastic medication really	30	486
G: we tried to get to see the consultant and we couldn't get to see the consultant down there	14	226-227
F: I wish the doctor would have listened to me because I've been going to the doctor for years and telling him that Joseph needs help and he wouldn't listen...you just feel as if you're banging your head against a brick wall isn't it because you know you've got a problem and you're talking to somebody and they can't understand...he could have said to me, "I can't help you, but I can tell you who can help you" but he didn't say, he just said he couldn't help and left it like that	7	112-121

Professional power

A: (Son) totally broke down until the doctor stopped the whole thing	30	682
C: I think this team helped us a lot, so it's like now the way I feel it's like they gave me my son back, because the moment he came back he was different	31	507-508
F: she was a lovely little lady and she really kick started a lot of things	1	7-8
F: they diagnosed him with um schizophrenia and then he got some medicine, so you know that's helped as well	14	225-226
F: he wasn't well, wasn't well until he got the medicine	30	492
G: The consultant doctor lady is very good she's very approachable you know, I mean if I rang her up and said can we come and see you, she'd let you go and see her	14	220-221

Professional lack of power

G: even had some of the sort of health people who tried to help him, I mean even (care coordinator) she's been good, occasionally you could tell she was feeling a bit, well what can I do to make this boy buck up a bit?	22	359-361
G: there was um a sort of psychiatrist person down there was trying to help him, but she, she did try quite	12	192-194

hard actually, but she just couldn't, more or less sort of gave up I think, he was just too difficult for her		
G: when we saw the doctor he went through like a script and we only got to see him sort of once every once a month at the most, sometimes it was longer than that and he just seemed to say "oh well we'll try this and this and we'll try that, what do you think?" sort of thing, well I don't know you're the doctor!	15	232-235
Family/community involvement and influence		
A: He's just like down the road at everybody's house, but nobody knows where he's gone	5	113
A: Like family members cos my mum, his mum, my sisters or whatever at one point everyone had different opinions about his problem and everybody was telling each person telling A how to deal with it and maybe every single person's view on it is different and that confused him	29	659-661
A: It was my partner who told me that he was walking the street trying to sell everything that he had just selling things you know what I mean and people thinking um saying "we saw him walking the streets and he was doing this and doing that"	14	317-319
A: I don't think he understands how to control a relationship you know what I mean, not control but to be in one...7 You know what I mean, I think the girls have more control over him		151-154
A: Ryan wants to see his mum but she's never been a mum kind of thing and she'll give him advice, weird advice just cos she's his mum he'll listen to her	21	473-475
A: They was trying to help I think but they didn't see that something was directly wrong with him. But they thought God, religion, this, that would get him out of it, but I was trying to explain I spoke to one and I said "just tell him leave the religious thing let's make him do some more things, go cinema whatever this, that" then again he was asking "Dad can I go to this church?" he always goes church almost every day of the week. I think just leave it alone for a while you don't need to go there every week you know what I mean...you have like things like Pastors phoning who want to come down to the house and stuff like that and I'll say "no they aint coming down" you know what I mean, but they think they're helping him with this religion thing but I just think...cos I was just shouting down the phone to them "just leave him alone" you know what I mean	17	371-380
A: After you'd done convincing him and then somebody else would undone, undo the whole thing you know what I mean	16	364
D: we was all going down to see him nearly every day I think it was, I think they managed really well cos nobody ever had a problem you know if you said like "you go and visit cos I'm going to so	9	141-143

and so” so everybody pulled together		
E: with this happening they do realise Steve’s not right, his cousins, he can’t do the things that his cousins do, or that we all take for granted. I think that’s made them realise a lot of things about Steve...I find that they’re more open to give support	11	183-189
E: I’ve always said to Steve, he’s not the one with special needs, it’s society with special needs, cos they’re the ones that make things difficult for him	35	570-572
F: we’ve got loads of relatives but people don’t help each other that much, they help their own families mainly...I don’t know if they’ve got problems in their family as well, I don’t know cos you know they might not tell me cos everybody looks after their own really	25	416-420

Son’s responsibility, under his control

A: I thought to myself “how can he...” cos Ryan aint stupid you know what I mean and I think to myself “how did you make yourself turn in to this?” you know what I mean, I kind of say to him “how did that happen Ryan?” you know what I mean “you’re not stupid” this that and whatever.	13	293-296
E: Steve’s Dad in particular is very ignorant to it, he thinks Steve should just snap out of it.	10	168-169
E: I just want him to try and help himself	16	255
G: we think sometimes perhaps he’s afraid, sounds daft, he’s afraid of getting better because then he might have more sort of responsibility and have to you know start looking for a job and things like that and he’s almost afraid of that perhaps	26	427-430

3. Confusion and uncertainty

About symptoms

A: At one point everyone had different opinions about his problem and everybody was telling each person telling Ryan how to deal with it and maybe every single person’s view on it is different and that confused him	29	659-661
A: Sometimes I think it’s like uh selective memory you know, what he wants to remember	2	28
A: Like he’ll have a wash, then he’ll stand up, I’ll see him you know what I mean he doesn’t know I’m watching3 sometimes but I’ll see him just standing there and it’s like he’s trying to work out what to do next		64-66
C: “I don’t know what is happening to my son”	9	135
C: usually when I take him to the reviews they explain what is happening erm and	11	169-172

(care coordinator) did, and he did post some information on psychosis, yes they explained all that, it's only that I am not medically trained but er I could understand, but then the only tool I had was that I knew the person he was before		
C: "what's wrong with you?"	27	438
D: had a long period of weeks or months of really strange behaviour	25	416
D: I suppose I think somebody should've said you need to sit down and read about the negative symptoms because when they're happening, you sometimes haven't looked at any of the paperwork because you're just like, you just don't, so by the time it's already happened then you're looking at it, but you've already done it, do you get what I mean, so maybe a bit more encouragement that you know alright things are looking better because you whoever it is has come home, but you should be aware that this, this and this can be a possibility	27	437-442
E: I think I'm very ignorant to some of the issues. Steve's Dad in particular is very ignorant to it, he thinks Steve should just snap out of it... I don't know if it's because he wants to see him well and that's his way of dealing with it all, I don't know, he's just not understanding the issues	10	168-172
E: a couple of his grandparents because you know cos of the generation, they don't understand...I mean I've had comments like he was possessed and you know...I was angry at first but when I thought about it I know it's their generation and they're stupid (laughs) you know it's just different um generations you know ideas of what mental health is and you know the issues, I just didn't realise until them how different we all feel and think about it	12	198-206
E: One thing I've noticed, he doesn't listen to his music either, I was asking him why last night, I don't know he'll say "just cos I don't want to" so I said, just to see his reaction, "I'm gonna give your CDs away", he said "go on then"...	14	229-233
So I don't know what that's about		
E: he used to have the lamp on, doesn't have that on any more, I don't know why...he can't explain why or he won't	15	243-244
E: I thought he was just depressed	6	93
E: I think would be helpful if there was something in writing so when I do forget I can always refer back to it	5	78-79
F: I didn't understand it, I kept saying "why won't you speak up?", but looking back now I realise now he was ill, he couldn't manage, he couldn't, he just couldn't, he just spoke in a whisper	10	162-163
F: I think I thought he'd lost his mind, must have	20	333
F: Couldn't understand why at the time, strange behaviour, I thought he was mentally ill anyway	22	360
F: he wouldn't explain what was wrong either, he never told us anything, nor explained anything, we didn't know how he felt cos he never said, couldn't get him to explain anything, he just kept saying yes and no	25	406-408
G: I've heard of negative and positive, I'm a bit confused-you'd think positive would be something good	6	90-91

but it isn't actually

G: He'll say he can't remember things but I mean when his sister came back at the weekend and they were 27 432-435
talking about things they did you know when they were children and more recently and clearly he can remember
things and he says he's got no friends, all my friends never contact me, but they do

G: I don't know what's going on in his mind 26 430

About cause of problems

A: They say there's like anything can kick it off innit, like can start it...yeah it was probably from a long time ago36 799-801
and then something, the religious thing kinda kick start it

C: I think he was, um I think he was mentally ill, I wasn't sure whether it was the causal connection was the mental10 151-153
illness, first of all he was just naughty with other children....and then I realised that he was taking cannabis as well,
so I don't know whether the cannabis was the causal connection to each or if it's just something that happened through
natural occurrence

C: I just thought probably it was he was just hanging around, I think it was where we lived I think these drugs 13 205-213
were accessible easily, you just go downstairs, or you know you know, and get it, so I thought it was er just that and as well he he
hanged around with people who were slightly older than him, I think they were in their twenties...and these boys were...in crime...
so there was a combination of the mental health aspects and the crime aspects

C: maybe it's because I used to live to go to work or to go to study, in a way this you know whatever 24 394-395
I should invested into this child

F: I used to wonder what have I done that was wrong you know, have I brought him up wrong you know, where 10 165-166
have I gone wrong?

G: is it genetic? I mean in my side of the family my mother and I think her mother had er a depressed episode, 8 124-127
my mother was quite depressed, but not like him, she wasn't depressed for such a long period, but she had periods of it

About diagnosis

C: he was in trouble with the police before, so when I told them about that I think there was this theory that it's a3 40-56
behavioural problem because of the crime factor, so I think you know that delayed it because he was on that side,
and they sort of thought no it's just his behaviour... the Early Intervention team thought it was his behaviour problems,
so for a year it went like that, until he was transferred to the Early Intervention team here, when we moved here so he

had to switch teams, so his worker there now sort of agreed with me		
D: I thought he'd had a break down, um we never ever found out, we've never had a diagnosis, the closest diagnosis we had was one doctor said he was bipolar, and I did get paperwork off me own doctor and it did make sense, the symptoms were so similar it <u>did</u> make sense, and then another one was they said he was psychosis which was psychotic, that half made a bit of sense but it didn't explain the other stuff, I think I was more inclined to believe it was bipolar and I dunno I don't know what's made him like he is now, you know at first it was obviously the medication to calm him down, but he's had a lower dose of medication now so I don't know, maybe that's just part of him getting better, you know	4-5	65-72
D: when he was in the hospital sometimes you get no information and I think that's when people need support the most, when somebody's first sectioned, cos you've got no idea and you really think that you're gonna go up there and they're gonna say "right, this is what's wrong with him and there's his diagnosis", we were going up there week after week "no, don't know what's wrong with him, no" and it was horrible and in the end as I said the closest diagnosis we got was bipolar and then it was all psychosis, and then even Adam said "nobody's mentioned bipolar again"	22	353-359
D: at that time I would've liked more information, as to you know I mean I knew that they could section him and it was seven, seven days, then they can do it for the 28, then after the 28 it was six months, but that was it, but nobody ever was able to sit down and say "you know don't get your hopes up and think that you're going to get a diagnosis when you go back because it doesn't work like that, and don't think that you know he's going to get better over night, this can be a long process" you know I would've liked somebody to have been able to tell me more <u>then</u> you know because obviously by the time he's at this stage and he's at home I've found out everything I need to anyway, but I think for carers and families that when it first happens that's when they need plenty of input of about what is actually happening	22-23	363-372
F: they said they couldn't find anything wrong with him and discharged... I felt a bit lost innit, you've tried and you're still banging your head against a brick wall	22	366-368
About services		
A: doctors, psychiatrists, he had all them things that was happening before you know what I mean educational psychiatrist...psychologists?...or psychologists and behavioural psychologists, psychiatrists	4	74-76
E: If I didn't work in the field I wouldn't know about any of the issues, I wouldn't know what questions to ask,	17	279-283

I wouldn't know where to go, who to approach if I needed support or if I need information or if I'm not sure about something, so you know working in the field it's really beneficial to me because there's a lot of people um in the services or family are carers and they don't know anything about mental health, who to go to, what questions to ask

F: I didn't know there was that much help, well I knew there was help out there but how to access the help 12 195-197

I didn't know, cos I thought that if I phoned my doctor he would help but he didn't

G: he went to the sort of um the local psychology unit I suppose...and we were under the sort of psychiatrist there 1 10-13

G: before the Early Intervention Service, there was um a sort of psychiatrist person down there was 12 192-193
trying to help him

G: I always get confused between psychiatrists and psychologists, I think it's a clinical psychologist 17 265

About medication

C: I think they also changed the medication, and from the time they changed the medication he has been better. 6 87-90
Initially he was on another type of medication, I'm not medically trained I don't know what sort of medication it was but maybe he didn't get on well very much with that one and he...now he's ok

D: they told us when he was on the depot that you know you need to be you know get yourself up a bit to start doing 5 77-81
things and you can put weight on but he's actually off that depot now, he's on tablets and you know he has had better days, so the whole idea of putting him on the tablets was to like even him out a bit you know so that he would be more aware, but then other days I think well I can't see much difference, he'd still sleep in the day if you let him

E: affected the family, they don't agree with medication so they didn't like the fact that Steve's on medication at the 10 166-
167
moment, but when I explained to them, they still don't like the that fact he's on medication

G: he's worried that the medication he's on is um affecting his brain and we don't really know how it works, and we 3-4 50-52
have asked the question and that hasn't really been explained particularly well

G: Well obviously we're a bit worried about er I mean I think when he first the first doctor who came 29 474-
483
from the Early Intervention service saw Andrew sort of on his own and whether Andrew had got it not quite right cos he seemed to have said to him well this antipsychotic medication you'll have to be on that till you're about 35 and it's going to reduce the volume of your brain! Now whether the doctor actually said that to him...but Andrew was really alarmed and so were we by that!... And we asked (psychiatrist) and she said "well we don't think he'll need to be on the medication for anything like that long, maybe we don't know but perhaps 2 or 3 years and we don't" I think she said it won't shrink your brain

G: Whether that's cos of the medication I don't know	19	311
G: he's actually said why am I on antipsychotic medication, I don't hear voices, I haven't threatened to go out and stab somebody or anything like that, and we are er to be honest a little bit puzzled and concerned by that...Well, presumably they trying to...the name Early Intervention..is to stop that happening, presumably I don't know	6	94-99
About how best to help		
A: I just did what I thought was best for him at the time	13	289-290
A: sometimes I think about taking his phone away but I thought no I can't do that cos I can't contact him and he'll feel like I'm trying to take over him, his life and everything	10	225-227
C: had to work, and sometimes I would go away for two, three days and everywhere I am I would worry what is happening to him and when I come back you know it was getting worse and worse and worse and worse obviously as a mother you would love to care for your son but there was a time I was torn in between either care for him and at the same time I've got to go to work	1	7-11
C: I was in a dilemma really because I didn't want Carl to be with these people and I didn't want him to continue so I would go and report every time I would see something I would go and report this (to police)	13	213-215
C: I didn't know what to do with him	17	268
D: you can't force it cos you know, you keep going up and going "come down, come down" you're going on at him and nagging him and I don't think he needs the added pressure, but then I'll say to his girlfriend "go and tell him now" or then I'll go up and go "look you're taking the piss now, don't spend the day in bed, come down here" you know we try and make a joke of it you know "stop being antisocial and get downstairs and come and sit with us lot" you know erm but he'll do what he wants to do I'm not going to force him to do anything, I wouldn't let him sit up there on his own for days on end but if I think he needs a bit of space on his own we'll leave him	10	154-161
E: I just encourage it you know when I know that they wanna do something with him I'll try and encourage him. I just don't want him to feel that I'm forcing him	18	298-300
F: he had acupuncture, but it didn't help, cos we didn't know exactly what was wrong so we were trying everything	25	403-404
G: I mean we were clutching at straws all over the place, trying to you know to do our best to try and get help for him	13	208-209
G: he was planning to stop overnight which we though oh is that a good idea, you know we didn't	28	451-454

sort of say well you mustn't go overnight, anyway he rang up and said actually I'm coming back tonight Dad cos I don't feel very well, which I think was the right thing to do

About recognition and appreciation

C: there was a time when I was left with the you know...really think this child doesn't care how I feel... but now I realise he cares about how I feel so that helps me	24	392-394
C: he sort of appreciates, that ok if mum did not call the police for me I would probably have been dead I think he knows that	30	490-492
D: I will always be the same whichever way they want me, emotionally or physically, I'll help them as much as I can you know because they you know you wanna guide them as they go on and do things with their own life, but I just think that they'll be there for their kids like I was for them, cos they will appreciate it you know, even if they don't appreciate it now they will in the future	21	332-336
E: I'm only mum when he wants something	21	340
E: at least I know that he's ok...which he doesn't appreciate sometimes	33	540

About the future

C: he was at a point whereby I wasn't so sure what was going to happen to him	11	179
C: I felt terrible, it worried me sick, because I didn't know what to do now	3	49
D: they just said that things will get better as you go along	8	126
D: just horrible really because you don't know how long this will last, that's what does your head in, will they get better, will they stay the same? That's, are they going to get sick again? The worst bit I think's not knowing if they're going to get better, if you're going to see improvements. That's I think that's the worst bit.	8	121-124
E: I worry in case something happens to me what's going to happen to Steve	9	147
E: I just worry you know "will he ever get a job?, will he ever find a girlfriend?"	34	563-564
F: what's he going to do, I'm not going to be around all the while, he needs to socialise and make some friends for himself	15	241-242
F: I didn't know when he was going to recover, you know I didn't know, I prayed and hoped that God would help him but I didn't know that he was going to come round so well as he's done now	17	270-272
F: I'm just hoping that there's hope at the end	5	83
F: I said "don't worry about it, he's going to be alright" but you know, I didn't know if he was	27	437-438

G: we'd like to sort of know what to expect, we we try and be optimistic, I mean they've assured us he will be alright after I think it's like a three year program they do isn't it?	29	470-472
G: we're a bit in unknown, we don't know what to expect	5	76

4. Impact of beliefs, expectations and values

Fear of others' perceptions

A: I was shocked that he swore in front of everybody	4	93
A: you've got all your nephews and all that round there who was just realising what was happening and they started giggling and laughing kind of thing and I'd say to him "leave it now" but A's praying so when he was starting it would last 10, 15 minutes but it was going on and on and on and on you know what I mean I was trying to say "don't do it" he kinda went back into his kind of thing	32	715-719
C: there was a time whereby I thought I would not even ask him to come because of the way he looked	17	270-271
E: I just don't want anyone to be looking at Steve and you know judging him, because of his appearance	26	424-425
E: I've always said to Steve, he's not the one with special needs, it's society with special needs, cos they're the ones that make things difficult for him	35	570-572
F: Just people who have said that you know they know the family and they've seen them on the street and they say "oh he doesn't look right, you know and somebody says "oh he doesn't look right at all, something's the matter with him, he's not right at all"...It's very hurtful because we can't help you know	28	452-456

Role of expectations in service evaluation

A: I've never dealt with this before I don't know how it goes	38	851
C: since he has been working with the Early Intervention team you know you couldn't wish for anything better they tried by all means, he has had three....um care, case workers, one young girl was getting married and then going away and then the other one was retiring (laughs) and we ended up with (case worker), yes so the three of them worked collectively with him and things just started getting better and better	4	67-71
C: I think it's just a team of people who try and deliver, outstanding service I must say, yeah... and even if I leave a message to say "it's Carl's mum, I want to speak to (care coordinator)" he will ring back, when he's you know when he's back	10	163-165
C: I didn't even expect a reply, well you would expect it but maybe not so prompt...	31	513-519

I was so so surprised in most services you ring or if you don't speak to an answer phone you ring until you ring and ring and ring, but with this team you ring once or twice and somebody picks the phone so so there's something which is magical about the team which is you know I really do appreciate that

C: there are some negative issues but it didn't become you know I look at it this way, he's not the only one, this is a thing that is affecting a lot of parents and er thank God we live in a society whereby he gets help 30 501-503

E: I mean when I used to claim the Carers Allowance because he was on a higher rate DLA, and because I work full time it was taken away, and I think that is so unfair, you know, we're still carers, it never stops, so I don't see why we should be penalised because we want to work, at the end of the day we're saving the government billions 31 501-504

E: I work with patients every day and I've never stopped to think, how do the families feel? And now I know...I take it for granted what they tell me or you know when they tell me they can't cope or they need more support, and now I can appreciate what they've gone through 33 545-549

G: we were grateful at that point to get any sort of help 2 17-18

G: with EIS it's much more structured...and helpful, it's not perfect but um...I mean there's nothing really bad at all 13 209-214
I want to make that quite clear, we think they're *really* good and we're *really* grateful

Trusting their own judgement

A: I just did what I thought was best for him at the time 13 289-290

C: I was trying to fight to take him out of that, so that in the end the police helped me, they say, because they knew that I if I saw anything I would come and report so they sort of help me to say, every time we see him we will search him...so after that I thought "mm, let me, let us move and go to try another area"... I had to persevere and just fight through to say no but at the same time it also got me into trouble with my other children 14-15 224-240

C: this is how I'm doing it...but you know people who are around you might want to give those ideas so that you know you you adopt that line of thought.... So as an African and as a woman you also suffer torture from cultural norms and you have got to think ahead and liberate yourself from that line of thought and say I what I think I know is right 17 282-287

C: I ended up saying "no this is my child I actually gave birth to him, so even though you are also my children but I think I have got a right" 18 293-294

F: I know he needed lots of love, it's a time when he needed lots of love isn't it? 11 185-186

G: in hindsight it was a mistake him going, but I mean if we'd have said we don't think it's a good idea for you to go to university and stopped him going he would I think he would have become ill anyway and he would have blamed us and said "oh it was because you didn't let me go to university" 24 389-392

Role of beliefs in coping

- C: the other thing that helped me is that cultural you know society here in England, English society 25 401-411
you know does not brand women as if you are the wrong doer...So I could tell as story, like I am telling you know, and you would, you could also listen "ok that's not your fault, that's not your fault" unlike if I was talking to my own people, they are busy building up to say "is it because the father's not there?" or these are children of single parents or things like that...so society, the way the British society and the way of living as a woman, it made feel stronger because you are also regarded as a person in your own opinion with choices as an individual as opposed to my own culture whereby you are a social misfit if you don't have a husband
- C: I said "it's never too late, you can jump back from anything" 22 363
- C: if I have a little cry a bit I will become stronger 16 257
- C: I didn't count on ok I must find somebody else to help me look after the children, I said it has 23 371-374
got to be me because er if people can take away your husband of 24 years, anything can happen even in future so I got to an extent whereby I didn't trust anybody
- D: you can't blame the past for how you decide to live your life, you can't you know sometimes it's 20 327-330
it's circumstances don't help things but make the most of each situation no matter how bad it is, life goes on you know, we only get life once it's not a rehearsal so I think you've just gotta make the most of it haven't ya
- D: I'm quite laid back in that I just accept that what's meant to be, I don't find it a major problem you 6 95-96
just deal with you know whatever comes along
- D: I've got a house full of people, you just go into robot mode, and have to do, and just have 8 130-134
to be as normal, you've got no choice, cos I've got other kids here as well, you know his girlfriend was pregnant, my other son's girlfriend she was pregnant, there was too much going on so you know you have to just you can't fall down, break down because you're no good to anybody then
- F: one thing that helped me was prayer you know, cos I go to church and I go to prayer meeting and pray and ask 13 212-214
God to help, and I've been praying for him and then I think God just changed the situation

5. Coming to terms

Denial

- A: in hospital even the um doctors saying "is there something wrong with him?" you know what I 33 748-751
mean and I said "nah" I'd just say no cos at that time he wasn't taking no medication or nothing like that no one was involved you know what I mean it was like "no there's nothing wrong with him" but I think they could see there was something wrong
- A: Something, something was up you know what I mean, but you know he's got other people 37 829-832

who notice that and they tell you “what’s wrong with Ryan?” but you don’t want to say nothing’s wrong with him you know so like “nothing’s wrong” you know what I mean...and then other members of the family say “he needs help” this, that and I said “nah, he’s alright, I’ll deal with it”

C: I knew at the at the back of my mind that something was wrong, but initially you don’t want to believe it and 21 342-348
 you are refusing to believe it you think ok it’s just a rough patch or something... sort of don’t want to face the inevitable and yet it is there but it also it still comes to you let’s say you are with others or at work or you are in the middle of drinking a cup of tea, you think about it, it sort of commands you

E: that’s when I realised something was wrong...That he was in crisis, but um it was all building up over the past2 31-33
 couple of years

F: I didn’t know what was wrong for a long time. I thought well, I didn’t even think he had a problem 4 62-63
 for a long time I just thought, I’ll just go and help him really

F: I didn’t really think he was ill, but I still went and got help just to supervise and to observe you know, what’s this,5 73-74
 it took me quite a while to realise that he needs help

Moment of realisation

A: that’s when I first, that’s when I first noticed something before the actually psychosis hit him 11 244-245

A: he actually kind of broke down right there I’ve never seen it happen before it was like a shock 30 679-680

C: when I first saw actually that something was wrong, we were not living here we were living in (town) 2 22-28
 he would laugh in such a way that maybe he was laughing with somebody and I would come out to check, no he was laughing with himself, or I would see him stand just in front of the mirror gazing for some time, you know you look at the mirror and then it’s probably two or three minutes and then you go, but then he was stood there for 20, 30 minutes just looking in the mirror, so that time I kind of knew that there was something wrong.

D: the beginning when somebody first gets ill because I think that’s such a shock, you haven’t 25 413-417
 got no idea what’s coming, you just haven’t, you haven’t got a clue, all of a sudden you know, especially when the person’s really ill and you’ve had to get them sectioned in the first place and by that stage you’ve had a long period of weeks or months of really strange behaviour that becomes to like a peak

E: that’s when I realised something was wrong...That he was in crisis, but um it was all building up over the past couple2 31-33
 of years

F: one day I thought he can’t be well cos he’s always smart looking you know, he was looking shabby 4 64-65

Pain and suffering

C: It was devastating for me	26	430
C: he (husband) wouldn't have liked me to suffer the way I am suffering	18	289
E: it's been devastating for all the family	11	177
E: it's all just been really...it's been awful, all through it	33	544
F: like your heart is bleeding in your heart really	10	154
F: Well just terrible, it was just the word to describe it is just terrible	21	335
F: "distressed"	11	166
	13	212
	17	271
G: to be with him all day you know is quite er debilitating really	20	322
G: we were obviously distressed at the time	33	542

Acceptance

D: no matter what happens you just get on with it and just deal with every day as it comes	9	147-148
D: by the time he was sectioned I felt so guilty for doing it, but I knew I needed to do it	26	418-419
E: it's not something to be frightened of it's something it could happen to any of us	13	211
E: obviously I'll just have to come to terms with it	21	342

Alteration of roles/status

A: He's not as close with his younger brother as before. B, his brother, was like at first...I dunno it's like he's not bothered, but he is bothered...and even his friends that come to see Ryan normally now come to see B more, I noticed instead of Ryan you know what I mean. And Ryan is always phoning other people, before they used to phone him but he's trying to make contact with them.	8	392-396
D: we're all alright, we're all used to each other's ways now	9	145
E: often everything has to begin round Steve and sometimes I think I pay more attention to Steve than I do his brother	10	155-156
E: it has brought us (family) closer together	11	177
G: in a way I suppose I'm sort of closer to him	23	365

Impact on emotional state

- Mixture of anger and pity

A: Kind of pissed off a bit cos I thought to myself “how can he...” cos Ryan aint stupid you know what I mean and I think to myself “how did you make yourself turn in to this?” you know what I mean, I kind of say to him “how did that happen Ryan?” you know what I mean “you’re not stupid” this that and whatever. I can get quite angry about it you know what I mean. 13 293-296

D: I ended up shouting at him and going you know “fuck’s sake I’m not going to keep running about blah blah blah” you know me head’s thudding and you’re going on and I really did go mad at him... I just thought what a shame, he’s so sick 7 111-115

E: Sometimes I shout... Then Steve shouts back, or he’ll just ignore me and then I’ll start feeling guilty for shouting24 399-402
cos I know it’s not his fault

G: we get sort of upset, we’ve even said to him “well think of other people in your family you’re you’re being selfish”, you have to sort of remind yourself that he’s ill 18 285-286

- Sadness/Depression

C: I was so...I was so depressed always 19 316

C: sometimes I would feel as if I would break down 16 257-258

D: It just brings you back down again and realise (tearful) even though he’s at home and he’s a lot better he’s not8 118-119

E: I feel like I’m mourning for the old Steve ...sometimes I find it hard to come to terms with what what’s happened8 131-132
over the past three months

F: it was very heart rending, I was so distressed, I think it was like a grief that you’ve lost somebody.... 9 138-139

G: you start to feel a bit depressed 20 324

G: I sort of felt sort of depressed about it really 22 353

- Guilt/self-blame

C: maybe it’s because I used to live to go to work or to go to study, in a way this you know whatever I should invested into this child 24 395-396

E: Sometimes I feel angry...like I’m being punished... Maybe I blame myself I dunno why but sometimes 28 452-456

I you know why didn't I see what was happening, why couldn't I have...you know caught onto the fact that Steve's gone into crisis, I just feel sometimes I should know better, that I missed all the signs and it was in my face

F: Sometimes I used to wonder what have I done that was wrong you know, have I brought him up wrong 10 165-166
you know, where have I gone wrong?

G: sometimes you have to go out and just to try, you can't forget about the situation but you have to go out to have a21 329-334
break but then you feel a bit guilty about it...I think of sort of well he's at home in that state and I'm sort of trying to
walk away from it

G: mean in hindsight it was a mistake him going 24 389

- Frustration

E: it's just frustrating, I know it's going to take time but I wish it would just hurry up 19 315

G: we go on this bike ride on the tow path and he'll come to say a junction and he'll say 19 306-307
"which was do we go Dad?" and I'll say "well you've been here sort of 20 times"

Feeling alone

C: I was so desperate, I felt like I was alone because you know wherever I was thinking of getting 3 45-47
help I couldn't get it but I was so sure there was something wrong with my son

D: I did have good friends who are supportive, but I still think that it's very lonely, so no matter how 23 379-381
supportive they are, they can't feel what you're feeling

E: I'm feeling a lot more supported, but I still feel as though I'm alone, I'm the only person in the world that's going 9 138-139
through it

F: you think well, like you're the only person
9 152

G: I remember one night coming home from work, hadn't had the best day at work anyway and he 20 325-327
was just crouched down in the hallway and I thought "Oh God this is..." (pause) although other people must go through this I don't
know?

Burden

C: it made me feel you know I had this huge you know problem on me 15 238-239

C: It was just too heavy for for me	18	299
C: it takes a <u>lot</u> ...it takes a lot (laughs) there was a time when it was only, I don't drink, if was you know, if I drank I would have gone off the rails because it was <u>so</u> much...so much on me, so much in me that...that well...what can you do?	30	494-496
C: it wasn't easy, it wasn't easy	32	520
E: is just...too much...to be dealing with	3	50
F: it's a burden really, you're burdened and distressed	10	153-154
F: It's a burden, you're burdened out	32	531
G: it takes some of the pressure off us, I mean just to be with him all the time is sort of is very stressful	3	37-38

Hope

C: if I can accumulate money I could send him even to a private school to get tuition in anything, privately, even if it is drama or something, so that he can jump that rough patch, and say "this is what happened to me and if my mum can afford to go and acquire this for me then probably it makes me feel better" so I kind of think about all these things a lot (laughs) yeah to say how best can I help him	28	466-470
D: the other day she said "Is there anything I can do for you, Adam?" He said no. "Cos I'm really, really eager and I want to do things, please, I just want to come and you say 'yes, can you do this for me'" I said, you know "there will come a day when he will ask you"	21-22	349-352
E: I'll just have to hope, live in hope that um that will come back	21	343
F: I'm just hoping that there's hope at the end you know but he's improved such a lot, because he dropped out of church as well, but now he's started to come back to church	5	83-84
G: I mean he has improved he is I think he is, touch wood, he's (laughs) sort of slowly getting better	3	38-39
G: we try and be optimistic, I mean they've assured us he will be alright	29	470-471
G: we're hopeful that will bring him on a bit more again	17	269

Learning

C: I learned how to cope in the process yeah, so so if I were to write a book I think it would be a very thick book (laughs) about it and it's made me stronger really	30	499-500
E: what it's taught me is how families feel, you know I work with patients every day and I've never stopped to think, how do the families feel? And now I know...I take it for granted what they tell me or you know when they tell me they can't cope or they need more support, and now I can appreciate what they've gone through.. I think I'm more, I dunno what word to	33-34	544-55

use.....empathy, I don't know, I'm sure I work differently with them now

6. Coping strategies

Just do it-not a choice

A: I'm the kind of person that I get on with things	9	189
C: I had to persevere and just fight through	15	239
C: I kept saying you have got to be strong for the children, I still have to be strong for them yeah	16	258-259
C: I just forged ahead	18	290
C: I learned how to cope in the process yeah, so so if I were to write a book I think it would be a very thick book	30	499-500
D: I just accept that what's meant to be, I don't find it a major problem you just deal with you know whatever comes along	6	95-96
D: you just go into robot mode, and <u>have</u> to do, and just have to be as normal, you've got no choice	8	130-131
E: I just get on with it	16	260

Humour

C: so that alone (laughs) was a problem	28	454
C: It takes a lot (laughs), there was a time if I drank I would have gone off the rails (laughs)	29	493
D: I mean like, we were laughing, and Adam was going "that's right that is mate, you know blah blah" I was howling, I was going "yeah you sound just like my son, don't worry about it, it's not a problem is it" and like you could have sides of it, there's other sides of it you'll find really funny because you know you have to laugh	25	401-404
E: Just worry till he comes home (laughs)	33	563
E: it was a complete waste of time, I approached the Learning Disabilities team, they said he's not severe enough, approached Children and Families, they said he doesn't meet the criteria, (laughs)	28	467-469

Support

- Sharing experiences

C: he's not the only one, this is a thing that is affecting a lot of parents	30	501-502
D: I had his girlfriend here and she was going exactly the same as me so we did have each other to talk to...	24	386-397

when you was having a bad day and you come home and one of the kids were really upset and you dealt with that, you ended up thinking “oh well actually I’m ok now by talking to them” that it’s not just you that’s affected and when you talk to people at the hospitals... It’s like um, going up the hospital, even other patients we got to talk to, you know I can remember one and he was like exactly the same as Adam, exactly, his whole thing

F: it’s quite helpful to know that other people are going through the same things like you know lots of carers you know, talking to other people as well 6 87-89

- Professional support

E: I felt that was really supportive for me and Steve...I was able to talk as well... And get information about certain 7 107-118 issues that I wasn’t aware of....just basically helped me to explore different options of dealing with Steve’s difficulties... And also maybe support for myself

E: Early Intervention are helpful...the contact they have with Steve, the regular contact, and with myself as well, you know just to know someone’s there to support if needed 30 493-496

- Support from friends and family

A: I had to have a conversation with everybody else saying “you can’t say this and say that and say that” and I’m saying this and you have to be on the same thing even though you don’t like it or whatever everyone has to work kinda together 30 662-664

C: two of my friends and they in fact they were really very strong for me ... they were really you know ...a rock on my side because when the whole world was saying I was wrong they said “no, you are not”, so it helped me cope 22 359-367

D: we was all going down to see him nearly every day I think it was, I think they managed really well cos nobody ever had a problem you know if you said like “you go and visit cos I’m going to so and so” so everybody pulled together 9 141-143

E: they (family) always buy me flowers cos I love flowers, or we’ll do something together... my colleagues as well, my friends...they’re just a shoulder really, as I said I work in the field so they’re very understanding of what’s going on 17 270-275

E: Talking...or just doing something as a family 24 387-388

Bottling up/avoidance

D: I couldn't let him see that it did (affect me)...um...cos he needed to get better and he didn't understand how he was so we couldn't really er show it just had to get on with it	7	109-110
E: I tend not to talk, I don't let anybody know how I'm feeling until I reach boiling point then I tell them that I'm not feeling too good or not coping	16	262-264
E: I try not to let things get to me too much because what's the point?	23	371-372
E: I tend to isolate myself as well	23	381
F: when my husband said negative things like I don't think he's going to get well, I don't say nothing I just leave it, just keep it to myself really. Not making the situation worse by telling, agreeing with him you know	32	523-525
F: can't cry outside, but you cry inside	10	154-155

Distraction

C: the study helped me cope as well because there was a time I was studying four degrees at one time (laughs) at one point because I would just bury myself in books thinking now I lost my husband and probably these books are the ones that are going to help me through, so it <u>did</u> help me because I had other things to do and I didn't count on ok I must find somebody else to help me look after the children, I said it has got to be me because er if people can take away your husband of 24 years, anything can happen even in future so I got to an extent whereby I didn't trust anybody... I felt I could do it I can do it, I can do it, I can do it	23	368-380
C: I could audit the 24 hours, what I am doing in the 24 hours, you know take account of everything what am I doing, what am I doing and that sort of helped me to cope	27	440-442
F: actually working (helped cope) because I needed to spend my money and to get him sorted out for clothes and things and my husband as well, a lot of our money went into his flat you know	13	204-205
F: going to the gym, I find is very refreshing, bums and tums class, nothing vigorous, just lie on the floor for half an hour, I felt refreshed and I felt rewarded as well...Walking as well, or just window shopping to relieve stress, not buying anything really cos I had no money, but just to walk around and have a look at things relieves stress like you know, wish you had this and that you know (laughs)	24	388-393
G: sometimes you have to go out and just to try, you can't forget about the situation but you have to go out to have a break	21	329-330
G: even going to work, I mean I don't particularly enjoy my job but to be in a different environment just for sort of seven hours I did find that helpful	21	338-339

Focusing on caring

- Communication

A: I find myself phoning him all the time	5	98
A: I'm constantly running round him, constantly phoning constantly making sure he's alright	29	645
A: I had to constantly talk to him about it	9	190-191
A: constantly talking, <u>constantly</u> talking to him	11	238
C: I kept talking to him	26	433
D: I talk to him, his girlfriend talks to him	15	238
D: Just talk to him	12	194
D: Just by talking and trying to get him to chat with the um, you know get involved in whatever we're talking about or whatever situation we are in	14	223-224
E: Sometimes I phone him just to check he's ok	33	538

- Attempts to motivate

A: Take him to places that I used to go with the kids and all that kind of stuff...I think the Nintendo Wii helped him because it were like exercise-and he weren't exercising...And it gives him something to concentrate on to beat the high score you know what I mean so that's what he's on it now you know it kinda keeps him a bit lively...cos he wasn't exercising or nothing innit so when the Wii came, it's not actually his it's my daughter's, and you just play with him-tennis whatever, all the Wii games, Wii sports and it now keeping him active cos when he was starting that and dribbling like that when he was playing the Wii he was like he can act like he's normal. Then he finishes playing the Wii and then it's back again. So when I notice that it's like yeah play the Wii, keep on playing it, but he kept on playing it and his concentration, you have to concentrate innit to get the highest score so he was alright.	12-13	264-279
C: I brought him the initial assessment that they use in the educational system...so he did the paper and I marked it	7	107-110
D: he's got the baby, take the baby up try to motivate him that way, or sometimes if I'm going out and I've got the car I'll say do you wanna come with me?"	12	194-196
D: we always say "look you've got a beautiful little son" you know we just try to encourage him	15	240
E: Just asking if he wants to do anything, or encourage him	15	246
E: I've joined him the gym	15	252

F: I've told him that you know he need to, how much money his holiday cost and he's got to bring that money to us every month otherwise he's not going to go and he does it 34 552-553

G: we tried to get him to to do things I mean I think physical exercise is important I mean at first he wouldn't go out at all on his own but now he does go out a bit for a walk or a jog, as I say I try to go out on bike rides with him 22 348-350

- Encouraging socialisation

A: even though I'm trying to get him out of the house I have to constantly phone him and make sure he's alright 21 455-456

A: and on his birthday he went to see Alicia Keys at the NIA, so I thought...I paid for that on his birthday and his friend and you know what I mean I was constantly on the phone checking on him you know what I mean I thought if he sees something like that he knows the police are round and he'll probably get feel better. It worked and didn't work you know what I mean. 20 445-448

D: you just spend more time trying to encourage him to spend time with other people you know if you're out you'll say "I'll come round and pick him up, but don't say I've said anything" and just you know or I'll just see one of his friends and say, you know er "he is awake you know er if you go round he will get up now" 11 168-171

- Supporting

A: If I don't prompt him and I don't remind him, you know what I mean, you just have to remember to remind him to just get him to do it like getting up in the morning and going showering I said "don't take long to shower" normally take a shower it's five minutes but he'll been in here for half an hour...if you leave him 2 37-40

A: just reminding him to get up and stuff and do things 3 53

D: I help him every day in any way that I can with anything, you know whether it's reminding him of "remember when we done this?" and "remember when we done that?" and you know "let's go and do this" so you know in that way I always encourage him...just bringing up things in the past that you know me and him would always find funny, if he doesn't find it funny the one day or couldn't remember it I'd try and mention it a week later because I'd know that when his old personality's coming back he would find that funny you know so I try those kinds of things 16 255-263

D: I think it's just, not just physical support, I think it's just moral and like you know trying to erm I dunno just to help them to get back to how they were and just be support really let them know that they've got somebody there that you know does care and you know whether it's emotionally or physically you know that they will help them, I think that's what's 17 273-276

important innit?

- D: I mean he can't he can't do his shoes up now and put his socks on because you know the weight 17 278-281
on his belly and that, make sure all his washing's done and you know his bath, his cooking, them kind of things he doesn't do
anymore you know somebody does it for him, everything's done for him really
- D: I've always done his washing and run his baths and done things like that for him 18 289
- E: he's lost some a lot of his social skills, his self care, you know um his personal care that's 1 14-16
gone down a lot so I'm constantly prompting and encouraging him with that
- E: just making suggestions like putting his clothes out the night before, reminding him 25 407-409
to out his dirty clothes in the basket, prompting him to have a bath, reminding him, explaining to him why
- F: At least once a week I was going over and actually buying things that he needs as well, 3 48-49
paying his gas bill in the winter cos he wasn't keeping himself warm
- F: we would go round and see his letters piling up on the table and we'd have to read them, 9 144-147
we'd have to open them and read them, Joseph wouldn't even read the letters, we used to open the letters and read them and sort it
out, try and sort the bills out you know
- F: helping Joseph as much as I can, going round once a week to help him sort the flat out, cos 17 276-278
if I leave it for any longer than four weeks, it will just get into a state, if he needs to go anywhere I have to go with him
- F: I'll have to go in and teach him some simple things really 31 510
- F: I used to buy things and go and help him to cook, come in the kitchen and bedside me and show him 21 342-343
what to do and things like that
- F: I started to keep a diary, to write things down...Using a calendar you know, cos he was missing 23 372-377
appointments as well, he never seemed to get anywhere in time, never got there the right day you know...I had to phone him up as
well, telephone him to remind him as well

Appendix J

Author's guidelines for submission to Psychology and Psychotherapy: Theory, Research and Practice

Psychology and Psychotherapy (PAPTRAP)

Notes for Contributors

Psychology and Psychotherapy: Theory Research and Practice (formerly The British Journal of Medical Psychology) is an international scientific journal with a focus on the psychological aspects of mental health difficulties and well-being; and psychological problems and their psychological treatments. We welcome submissions from mental health professionals and researchers from all relevant professional backgrounds. The Journal welcomes submissions of original high quality empirical research and rigorous theoretical papers of any theoretical provenance provided they have a bearing upon vulnerability to, adjustment to, assessment of, and recovery (assisted or otherwise) from psychological disorders. Submission of systematic reviews and other research reports which support evidence-based practice are also welcomed, as are relevant high quality analogue studies. The Journal thus aims to promote theoretical and research developments in the understanding of cognitive and emotional factors in psychological disorders, interpersonal attitudes, behaviour and relationships, and psychological therapies (including both process and outcome research) where mental health is concerned. Clinical or case studies will not normally be considered except where they illustrate particularly unusual forms of psychopathology or innovative forms of therapy and meet scientific criteria through appropriate use of single case experimental designs.

1. Circulation

The circulation of the Journal is worldwide. Papers are invited and encouraged from authors throughout the world.

2. Length

Papers should normally be no more than 5000 words (excluding the abstract, reference list, tables and figures), although the Editor retains discretion to publish papers beyond this length in cases where the clear and concise expression of the scientific content requires greater length.

3. Submission and reviewing

All manuscripts must be submitted via our [online peer review system](#). The Journal operates a policy of anonymous peer review.

4. Manuscript requirements

- Contributions must be typed in double spacing with wide margins. All sheets must be numbered.
- Tables should be typed in double spacing, each on a separate page with a self-explanatory title. Tables should be comprehensible without reference to the text. They should be placed at the end of the manuscript with their approximate locations indicated in the text.
- Figures can be included at the end of the document or attached as separate files, carefully labelled in initial capital/lower case lettering with symbols in a form consistent with text use. Unnecessary background patterns, lines and shading should be avoided. Captions should be listed on a separate sheet. The resolution of digital images must be at least 300 dpi.
- For articles containing original scientific research, a structured abstract of up to 250 words should be included with the headings: Objectives, Design, Methods, results, Conclusions. Review articles should use these headings: Purpose, Methods, Results, Conclusions. For further details please see the document below:

 Psychology and Psychotherapy: Theory, Research and Practice - Structured Abstract Information

- For reference citations, please use APA style. Particular care should be taken to ensure that references are accurate and complete. Give all journal titles in full.
- SI units must be used for all measurements, rounded off to practical values if appropriate, with the imperial equivalent in parentheses.
- In normal circumstances, effect size should be incorporated.
- Authors are requested to avoid the use of sexist language.
- Authors are responsible for acquiring written permission to publish lengthy quotations, illustrations, etc. for which they do not own copyright.

For guidelines on editorial style, please consult the APA Publication Manual published by the American Psychological Association.

5. Brief reports

These should be limited to 1000 words and may include research studies and theoretical, critical or review comments whose essential contribution can be made briefly. A summary of not more than 50 words should be provided.

6. Publication ethics

All submissions should follow the ethical submission guidelines outlined the the documents below:

 Ethical Publishing Principles – A Guideline for Authors

 Code of Ethics and Conduct (2006)

7. Supplementary data

Supplementary data too extensive for publication may be deposited with the British Library Document Supply Centre. Such material includes numerical data, computer programs, fuller details of case studies and experimental techniques. The material should be submitted to the Editor together with the article, for simultaneous refereeing.

8. Copyright

On acceptance of a paper submitted to a journal, authors will be requested to sign an appropriate assignment of copyright form. To find out more, please see our Copyright Information for Authors.