

**Can Caregiving Experiences be Understood Using an  
Attachment Framework in Early Psychosis?**

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## **UCL Doctorate in Clinical Psychology**

### **Thesis Declaration Form**

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Signature:

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Date: 1<sup>st</sup> July 2015

## **Overview**

This thesis is presented in three parts with an overall focus on caregiving relationships and responses in early psychosis. Part one presents a systematic review of the literature examining the efficacy of family interventions within early psychosis. The evidence reviewed suggests that family interventions can improve symptoms and general functioning in service users and may enhance relatives' overall experience of caregiving. However, there was equivocal evidence for relapse reduction or changes in the family environment. Further research is required to establish the key therapeutic components of family interventions that are most effective for whom. Part two is an empirical paper examining the role of caregiver attachment style on caregiving behaviours, attitudes and responses. The data suggests that attachment theory can contribute to our understanding of caregiving experiences, particularly caregiver distress, although further research is recommended. Finally, part three presents a critical appraisal of the investigation presented in the empirical paper. Consideration is given to a number of conceptual and methodological issues pertinent to this study and to caregiving and attachment research in general. The appraisal concludes with some personal reflections on the experience of conducting the project.

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**Part One: Literature Review**

**Do Family Interventions Improve Outcomes in Early Psychosis?**

**A Systematic Review**

## Abstract

**Aims:** Family interventions for psychosis (FIp) are effective in reducing both service user relapse and caregiver distress in people with schizophrenia-spectrum disorders. However, findings in relation to early psychosis groups have been inconsistent. This paper aims to explore the efficacy of FIp in improving outcomes for service users and relatives in early psychosis.

**Method:** A systematic review of articles that evaluated FIp in early psychosis with a clearly defined comparison group was completed. A combination of electronic database searches (using PsychINFO, PubMed, and CENTRAL), citation searches and hand searches of key journals was conducted. Peer-reviewed articles published in English from database inception to January 2015 were included. Methodological quality was assessed using the Effective Public Health Practice Project Quality Assessment Tool (EPHPP).

**Results:** Twenty-one papers from fifteen studies met inclusion criteria for review, the quality of which was rated moderate to strong (EPHPP). FIp reduced symptoms and increased functioning in service users, but the evidence for reducing relapse or days in hospital was equivocal. The subjective experience of caregiving improved for carers, but there was no evidence for change in levels of carer Expressed Emotion, communication style or general health.

**Conclusion:** The current findings indicate that FIp is an important intervention for early psychosis service users and their relatives. However, further research is required to establish which key therapeutic components of FIp are most effective for whom, in addition to understanding the mechanisms by which FIp might affect positive change.

## **Introduction**

Psychoses-spectrum disorders (including schizophrenia) are associated with substantial disability and social disadvantage (World Health Organisation, 1992). Despite a long history of research, such conditions continue to have a considerable impact on the individual as well as those who support them. Reforms in the mental health system, including a move from institutional to community and home-based care, have resulted in family members increasingly placed in informal caregiving roles for individuals with mental illness (Ohaeri, 2003).

The association between the family environment and service user outcomes in mental health was first documented in a seminal study by Brown (1959). Following discharge from psychiatric hospital, the type of environment a service user returned to was found to significantly influence subsequent relapse and readmission rates (Brown, 1959). A large body of literature has since replicated these findings, demonstrating robust associations between the familial environment and outcomes for people with psychoses-spectrum disorders (Bebbington & Kuipers, 1994; Butzlaff & Hooley, 1998). The construct of Expressed Emotion (EE) evolved from Brown's work as a way of measuring the interpersonal relationships between individuals with mental illness and their family members (Brown, 1985; Butzlaff & Hooley, 1998). 'High EE' comprises high levels of critical comments, hostility and/or emotional over-involvement (the tendency to be over-protective or intrusive). The predictive validity of EE on the course of psychosis is now well established: high EE in family members is associated with more frequent relapse, longer duration of illness and more frequent hospital admissions in service users with psychosis (Bebbington & Kuipers, 1994; Butzlaff & Hooley, 1998).

It is also recognised, however, that informal caregivers can play a crucial and positive role in enhancing the wellbeing of people with psychosis, facilitating service users' access to mental health services (Morgan et al., 2006), increasing treatment adherence

(Ramirez-Garcia, Chang, Young, Lopez & Jenkins, 2006), and enhancing response to psychological interventions (Garety et al., 2008). The value of family members in supporting a person with psychosis is increasingly acknowledged and they are considered to have an instrumental role in recovery (Bebbington & Kuipers, 1994; Bertrando et al., 1992).

Research in this area has more recently focused on outcomes for caregivers themselves. Families are often required to quickly adjust to the role of ‘caregiver’, one that they frequently report feeling underprepared for (Addington & Burnett, 2004). Supporting and caring for an individual with psychosis can be a challenging task and has been associated with increased levels of distress, anxiety and depression in relatives, particularly where family members have high EE (Fortune, Smith & Garvey, 2005; Kuipers, Onwumere & Bebbington, 2010; Jansen et al., 2014). High levels of distress can influence caregiving responses and coping styles, which in turn further impacts outcomes for service users themselves (Kuipers et al., 2010).

### **Family Intervention**

Understanding the contribution of the family milieu on the course of illness, together with an appreciation of the impact on those who provide care, underscores the importance of family interventions for psychosis (FIP). The format and approach across evidence-based family interventions varies, although comprise key features of psychoeducation, problem-solving and/or stress-reduction (Glick, Clarkin, Haas & Spencer, 1993; Kuipers et al., 1997). It is thought that FIP works on a number of levels: firstly by reducing high EE and family stress, in addition to improving skills in problem-solving and communication. The key therapeutic aim is to minimise the risk of relapse in service users via the use of adaptive coping strategies by relatives (Onwumere, Bebbington & Kuipers, 2011; Pharoah, Mari, Rathborne & Wong 2010).

A Cochrane Review (Pharoah et al., 2010), along with previous reviews and meta-analyses (e.g. Pharoah, Mari & Streiner, 2000; Pharoah, Rathbone, Mari & Streiner 2003; Pharoah, Rathbone, Mari, Streiner, 2006; Pitschel-Waltz, Leucht, Bauml, Kissling & Engel, 2004), concluded that FIp significantly reduces relapse and hospital readmission rates for people with schizophrenia-spectrum conditions and increases adherence to pharmacological treatments. FIp is a cost-effective intervention (Mihalpolous Magnus, Carter, Vos, 2004) and national treatment guidelines now recommend a family-inclusive approach in the treatment of all schizophrenia-related conditions (Gaebel, Weinmann, Satorius, Rutz & McIntyre, 2005; International Clinical Practice Guidelines for Early Psychosis, 2005; IRIS, 2012; NICE, 2014). Whilst the evidence for FIp for the broader schizophrenia-spectrum is strong, the effectiveness has primarily been shown in studies involving service-users who have mixed lengths of the illness – and predominantly those who have more long-term, chronic forms (for example those with an established schizophrenia diagnosis). There are significant differences for those with recent-onset psychosis in comparison to those affected by longer-term forms of the illness and such differences may impact the efficacy of FIp.

### **Early Psychosis**

The emergence of psychosis typically occurs in late adolescence to early adulthood (Lieberman & Fenton, 2000; Mueser & McGurk, 2004). Diagnostic ambiguity often follows a first episode and long-term outcomes are unclear (Addington, Addington & Patterson, 2006). Some people may only ever have a single episode, however approximately three quarters of individuals have further episodes and for some, this may advance to long-term conditions such as schizophrenia (Robinson et al., 1999; Wiersma, Nienhuis, Slooff & Giel, 1998). An increased number of episodes (or relapses) during the early stages of psychosis is associated with poorer clinical outcomes (Birchwood, Todd & Jackson, 1998; Emsley, Chiliza & Schoeman, 2008; Rabiner, Wegner & Kane, 1986) and problematic recovery

(Shrivastava et al., 2010). The greatest clinical deterioration has been shown to take place in the first five years of onset (Lieberman et al., 2001), which is now understood to be a 'critical period' (Birchwood et al., 1998). As such, there is a great need for early identification and effective treatment options to support those who might be at risk of developing psychosis, as well as those in the early stages of the illness, in order to ensure optimum outcomes (McGlashan et al., 2007).

Family interventions are particularly relevant for the early psychosis group. In the very early stages (or so-called 'prodromal' phase), pharmacological treatments might not yet be indicated and following a first episode, adherence to prescribed pharmacological treatments is generally very poor (Coldham, Addington & Addington, 2002). Furthermore, the early stages often occur at a time when many young people are still living at home (Fisher et al., 2008; Lobban, et al., 2013; Garety & Rigg, 2001), therefore family members are usually the first to notice changes and identify relapse indicators once the person has recovered from their first episode (Addington & Burnett, 2004; Jackson & McGorry, 2009).

In addition, caregivers who are both coming to terms with and growing in their understanding of a first episode may have different needs from a carer who has supported their relative over a longer timeline including multiple hospital admissions and relapse (as highlighted by Gleeson et al., 1999 and Collins, 2002). It is recognised that the early psychosis group have unique needs compared to those with longer forms of the illness. The efficacy of interventions within this group needs to be established independently of those with long-term conditions, as interventions based on treatments for those with longer-term conditions may not translate to this group.

## **Previous Reviews in Early psychosis**

Few reviews have directly examined the efficacy of Family Intervention in early psychosis. Bird et al., (2010) examined a small number of randomised controlled trials (N=3) looking at FIp offered within specialist early intervention for psychosis services. They found that service users in the family intervention group were less likely to relapse or be admitted to hospital at the end of treatment, compared to those receiving standard care. However, two other reviews examined a total of seven papers from six distinct trials and reported mixed findings (Askey, Gamble & Grey, 2007 & Penn, Waldheter, Perkins, Meuser, Lieberman, 2005). They included studies with less controlled designs, however three of the seven articles demonstrated no significant improvement with regard to service user or relative outcomes and one study indicated that service users' in low EE families actually showed a deterioration in symptoms following FIp (Linszen et al., 1996). Onwumere et al., (2011) also discuss the mixed findings for the early psychosis group in their recent review, highlighting the need for further research.

## **Current Review**

Family interventions have been shown to be beneficial for schizophrenia-spectrum disorders in reducing symptoms and illness duration as well as reducing EE and improving outcomes for caregivers. FIp is now a recommended treatment for all psychosis and schizophrenia conditions (Pharoah et al., 2010). However, the systematic reviews and meta-analyses that led to these recommendations were largely based on studies involving service users with mixed illness phase (and often long-term forms of the illness). Furthermore, previous reviews examining the early psychosis groups have suggested that there is limited and conflicting evidence for FIp within an early psychosis population (e.g. Askey et al., 2007, Onwumere et al., 2011, Penn et al., 2005). There have been a number of limitations to previous reviews, including not using a systematic search strategy (Askey et al., 2007),

only examining RCTs taking place within Early Intervention for Psychosis services (Bird et al., 2010), based on mixed-length illness (Pharaoh et al., 2010) or including multi-element interventions (Penn et al., 2005). It is crucial that the efficacy of FIp is clarified for this population. The aims of the current review are to update the evidence base and examine whether FIp improves outcomes for service users and caregivers within an early psychosis population. In addition, this review will include those ‘at risk’ of developing psychosis, recognising this is an important population requiring effective psychosocial interventions to improve long-term outcomes.

## **Method**

### **Search Strategy**

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA; Moher, Liberati, Tetzlaff & Altman, 2009) guidelines were followed in conducting this systematic review. Studies were identified through a combination of computerised database searches, citation searching and manual searches of bibliographies.

A systematic search of the literature for relevant articles published from database inception until January 31<sup>st</sup>, 2015 was performed using the databases PsychINFO, PubMed, and CENTRAL (Cochrane Library). Results were limited to English language and peer-reviewed journal articles. Preliminary searches using keywords within the broad categories of ‘family intervention’ and ‘psychosis or schizophrenia’ indicated that these two categories alone were over-inclusive. Restricting papers to those that also included keywords related to ‘at risk’ or ‘early psychosis’ did not change the number of relevant papers retrieved. A list of keywords and MeSH (Medical Subject Headings) terms was generated to identify studies that included family-based interventions for those ‘at risk’ of developing psychosis and those

who had experienced recent-onset psychosis. A comprehensive list of search terms was used to capture all variations within each of three categories (terms listed are given as examples): (i) psychosis / psychotic illness / schizophrenia, (ii) family intervention / psychoeducation / family therapy (iii) early / at risk / first episode. The search returned only papers that contained at least one term from each category (see Table 1 for full list of terms).

Table 1

*Detailed keyword search strategy*

<b>Schizophrenia</b>	<b>Family Intervention</b>	<b>Early or at risk population</b>
Schizophren*	Famil* intervention	Early
Psychos*	Famil* Therap*	At risk
Psychotic*	Famil* work	High risk
Schizoaffective	Psychoeducation	First episode
	Group Intervention	Prodrom*
	Group work	First onset
	Group Therap*	Critical period
		Initial

### **Eligibility Criteria and Study Selection**

**Inclusion Criteria.** The criteria for including studies within the review were as follows: (1) Studies evaluating a family intervention of any type (including family work, psychoeducation and family therapy) and of any duration; (2) Service user population defined as either ‘at risk’ (using validated assessment methods e.g. those with a family history of psychosis or displaying prodromal symptoms) or with a diagnosis of early psychosis (service users described as “first episode”, “early psychosis” or those service users within the first 5 years of diagnosis); (3) Quantitative studies with a clearly defined control or comparison group (for example RCTs or Clinical-Controlled trials) and (4) Studies

published in English, and in peer reviewed journals (abstracts, reviews, case reports, thesis dissertations and case studies were discounted).

**Exclusion Criteria.** Studies with no comparison group were excluded. In addition, studies where family interventions were offered as part of an integrated treatment, but where the methodology did not clearly identify, define and report outcomes in relation to a family intervention component were not included. For example, studies that described family interventions as part of a comprehensive early intervention programme, but did not clearly identify which service users or carers had received the FIp, or only evaluated the entire multi-component programme, were excluded.

### **Assessment of Methodological Quality**

The methodological rigour of each study was assessed using the Effective Public Health Practice Project Quality Assessment Tool (EPHPP). This tool assesses the quality of quantitative studies across six domains: selection bias, study design, confounding variables, blinding, data collection methods and withdrawals and dropouts. The EPHPP can evaluate a number of study designs, and has good content and construct validity (Jackson & Waters, 2005; Thomas, Ciliska, Dobbins & Micucci, 2004).

Following the EPHPP guidelines, each domain was rated as strong, moderate or weak, based on information reported in the paper. Fifty percent of papers were co-rated (by the author's supervisors, JO and MFA) with discrepancies in scoring discussed until an agreement was reached. A global rating was then calculated and each paper was rated as strong (no weak ratings), moderate (one weak rating) or weak (two or more weak ratings). Table 2 outlines the criteria for quality ratings for each of the six domains.

Table 2

*Quality Assessment Ratings for the Six Domains on the EPHPP*

Domain	Strong Rating	Moderate Rating	Weak Rating
Selection Bias	Participants are very likely to be representative of the target population and greater than 80% participation	Participants are at least somewhat likely to be representative of the target population and 60 - 79% participation	Participants are not likely to be representative of the target population; or there is less than 60% participation; or selection is not described; and the level of participation is not described
Study Design	RCTs and CCTs	Cohort analytic, case control, cohort design, or interrupted time series	Any other design or did not state the design used
Confounders	Controlled for at least 80% of relevant confounders	Controlled for 60 – 79% of relevant confounders	Less than 60% of confounders were controlled or not described
Blinding	The outcome assessor is blind and the study participants are not aware of the research question	Blinding of either outcome assessor or study participants; or blinding is not described	The outcome assessor is aware of the intervention status of participants and the study participants are aware of the research question
Data Collection Methods	The data collection tools have been shown to be valid and reliable	The data collection tools are valid but the data collection tools have not been shown to be reliable or reliability is not described	The data collection tools have not been shown to be valid or both reliability and validity are not described
Withdrawals and Dropouts	Follow-up rate is 80% or greater	Follow-up rate is 60 – 79%	Follow-up rate is less than 60% or if the withdrawals and drop-outs were not described

*Note:* RCT= Randomised Controlled Trials; CCT = Controlled Clinical Trials

## **Synthesis**

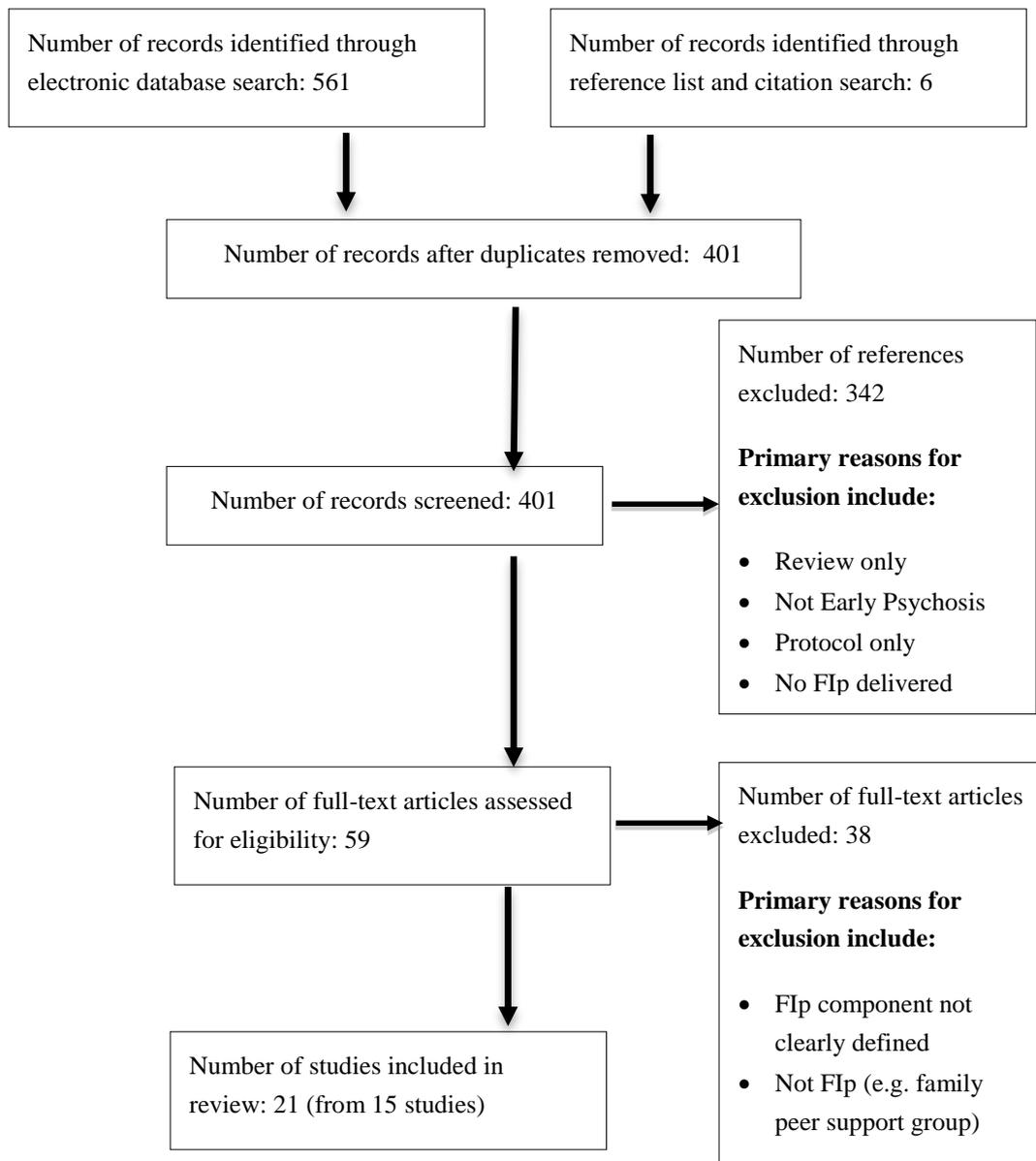
Following the quality assessment, a synthesis of studies was carried out, focusing on participant characteristics, study design, intervention, and outcomes reported for both service user and caregiver.

## **Results**

### **Study Selection**

The study selection process is outlined in Figure 1. After removing duplications, the electronic search generated 395 papers. Reference lists of relevant systematic reviews and papers were hand searched, generating a further six papers of interest. A total of 401 papers were screened by title and abstract, after which 342 were excluded.

The full-text articles of the 59 remaining papers were read in full and considered against the inclusion and exclusion criteria. These were all reviewed by the author plus one other (either MFA or JO). Disagreements were resolved via discussion. A further 37 papers were excluded after failing to meet all the eligibility criteria. Primary reasons for exclusion included: (1) the family intervention not being clearly defined in the method or analysis (e.g. reported as part of an integrated, multi-element service, meaning it was not possible to separate FI component in the analysis); (2) no comparison group; and (3) participants not meeting the 'early psychosis' criteria. This left a total of 21 papers to be included for this review.



**Figure 1.** Study selection and primary reasons for reference exclusion.

## Quality Assessment of Included Studies

Overall, the quality of the studies, as rated by the EPHPP, was good. All 21 papers were rated and 11 were classified as strong, 8 as moderate and 2 as weak (see Table 3). Data collection methods and study design were of particularly high quality, with 81% and 87% of papers rated as strong in these areas respectively. Confounds were also an area of relative strength, as studies generally reported and controlled for these. Participant selection bias was more mixed; most studies were representative of the target population, although referral pathways for older studies were occasionally less so (for example limited referral pathways in De Giacomo et al., 1997 and only male service users recruited in Zhang, Wang & Phillips, 1994). In addition, following the initial invitation to participate in research, many studies reported less than 80% participation in the trial, leading to most papers rated as moderate in this area. The majority of studies detailed the number of participants who consented, withdrew or dropped out, but high dropout rates in some studies, particularly after two years, meant that this was an area of weakness. On average, dropout rates ranged from 21% at six month follow-ups to 30% at two years or more. The highest dropout rate was Gleeson et al., (2010) where 67% of participants had dropped out by a 30-month follow up. However, in general papers took this into consideration, i.e. by using intent-to treat analyses. Blinding was the area where studies performed the least well, with all rated as moderate or weak, primarily because it is not feasible to blind participants to treatment allocation. Attempts were made to blind the assessing researcher in most studies, but again, this was not always possible, particularly those with longer follow-ups as papers reported service users unintentionally revealed which group they were in. Gleeson et al., (2010) was one of two studies to receive a weak rating, which was due to the high dropout rate at the final point of follow up (as detailed above) in addition to reporting, but not controlling for, two confounders; in comparison to controls, the FIp group were significantly more likely to be a) employed and b) residing with the service user. In addition, Rund et al., (1994) received a weak rating due to unreliable data collection methods (discussed later) and lack of blinding.

The EPHPP offers additional scales to assess treatment completion rates and intervention fidelity (although this is not including in the overall rating). Not all studies recorded this information, but for those that did, treatment completion was found to be generally weak (most studies reported that less than 60% of relatives completing the entire intervention), although variability across trials was high. Treatment fidelity however, was good, with 10 of the 15 studies reporting high consistency across the interventions (the others did not report whether consistency was monitored or not).

Table 3

*Quality Assessment of Reviewed Studies (using the EPHPP) N=21*

<b>STUDY</b>	<b>Selection Bias</b>	<b>Study Design</b>	<b>Confounders</b>	<b>Blinding</b>	<b>Data Collection Methods</b>	<b>Withdrawals and Drop-Outs</b>	<b>GLOBAL RATING</b>
Calvo et al., (2014)	M	S	S	M	S	S	<b>Strong</b>
Goldstein et al., (1978)	S	S	S	M	S	S	<b>Strong</b>
Linszen et al., (1996)	S	S	S	M	S	S	<b>Strong</b>
Lenoir et al., (2001)	M	S	S	M	S	M	<b>Strong</b>
Nugter et al., (1997a)	S	S	S	M	S	S	<b>Strong</b>
Nugter et al., (1997b)	S	S	S	M	S	S	<b>Strong</b>
McCann et al., (2013)	M	S	S	M	S	S	<b>Strong</b>
Miklowitz et al., (2014)	M	S	S	M	S	M	<b>Strong</b>
Rund et al., (1995)	M	M	M	M	S	S	<b>Strong</b>
So et al., (2006)	M	S	S	M	S	M	<b>Strong</b>
Smeerdijk et al., (2014)	M	S	S	M	M	M	<b>Strong</b>
Browning et al., (2013)	S	S	S	W	S	S	<b>Moderate</b>
Cozolino et al., (1988)	S	S	S	W	S	S	<b>Moderate</b>
De Giacomo et al., (1997)	M	S	W	M	S	M	<b>Moderate</b>
Leavey et al., (2004)	W	S	S	M	S	M	<b>Moderate</b>
Lenoir et al., (2002)	M	S	S	M	S	W	<b>Moderate</b>
O'Brien et al., (2014)	M	S	S	M	W	M	<b>Moderate</b>
Rossberg et al., (2010)	W	M	M	M	M	M	<b>Moderate</b>
Zhang et al., (1994)	M	S	W	M	S	S	<b>Moderate</b>
Gleeson et al., (2010)	M	S	W	M	S	W	<b>Weak</b>
Rund et al., (1994)	M	M	S	W	W	S	<b>Weak</b>

*Note.* S= Strong, M= moderate, W = weak.

Global Rating is calculated using information across all six domains: strong (no weak ratings), moderate (one weak rating) or weak (two or more weak ratings)

## **Study Characteristics**

This systematic review encompassed data from 21 articles, reporting findings from 15 distinct studies (study characteristics are detailed in Table 4). Fifteen distinct studies will be referred to and when separate or follow-up papers are being referenced this will be made clear. Seven studies were conducted in Europe, three in North America, two in Australia and two in China. Eleven studies employed randomised controlled designs and four used uncontrolled designs (e.g. clinical controlled trials; Linszen et al., 1994; Rossberg et al., 2010; Rund et al., 1994, 1995; So et al., 2006).

**Participant Characteristics.** Caregivers of 1279 service users took part in the 15 included trials, with a mean sample size of 85 (SD=69). One trial (O'Brien et al., 2014 & Miklowitz et al., 2014) examined those at risk of developing psychosis, whilst the remaining 14 examined those with early or first episode psychosis. Service users were between 12-35 years old, and three studies exclusively examined service users with 'early-onset' psychosis (those with onset under-18 years old; Browning et al., 2013; Calvo et al., 2014; & Rund et al., 1994 & 1995). Limited information was provided about the identified caregivers. From the studies that did note this information, carers were predominantly mothers (across four studies recording this data, 75% were mothers of service users), with an average age of 46 years (three studies recorded this) and generally lived with the person they cared for (across four studies, 79.2% lived with service user).

**Family Intervention.** The interventions comprised a mixture of individual family work (n=8), group work (n=5) or a mixture of both (n=2). Some interventions were delivered to carers only (Calvo et al., 2014; Cozolino et al., 2014; McCann, 2013; Smeerdijk et al., 2014; So et al., 2006), whilst others invited service users to join all or part of the intervention (De Giacomo et al, 1997; Goldstein et al., 1978; Linszen et al., 1994; O'Brien et al., 2014; Rossberg et al., 2010; Rund et al., 1994, 1995; Zhang et al., 1994). Three studies did not mention whether service users attended the sessions or not (Browning et al., 2013; Gleeson et al., 2010; Leavey et al., 2004).

The content of the interventions differed and no two studies described the same intervention protocol. Five studies were based on manualised interventions (manuals included: Falloon, 1984; Glick et al., 1993; Kuipers et al., 1997; McFarlane et al., 1995), whilst the remaining referenced study-specific protocols. However, in spite of the differences, there were shared commonalities: the majority of interventions included psychoeducation as a chief component (n=12), and many of these incorporated communication and problem-solving skills training. One study (Smeerdijk et al., 2014) comprised skills training based on the principles of motivational interviewing (MI), and one study (De Giacomo et al; 1997) used a systemic family therapy intervention, which specifically excluded any psychoeducational component.

In addition to the differing content, the 'dose' of intervention also varied between studies. Eleven trials examined a structured family intervention with a pre-determined number of sessions. Of these, Cozolino et al., (1998) was the shortest, comprising a one-off, three-hour psychoeducational workshop. For the remaining ten of these studies, the number of sessions ranged from 5 to 18 (mean = 9.3 sessions) and session duration ranged from 60 – 120 minutes, spanning between 5 weeks – 12 months. Four studies offered less structured session formats, offering flexible sessions over 18 – 24 months (Gleeson et al., 2010; Linszen et al., 1994; Rund et al., 1994; Zhang et al., 1994).

Table 4

*Characteristic of Included Studies (N=15)*

<b>Primary author, publication year and country of origin</b>	<b>N</b>	<b>Study Design</b>	<b>Patient descriptions and diagnosis</b>	<b>Family Intervention (FI) Description</b>	<b>FI Duration</b>	<b>Comparison Group (s)</b>	<b>Follow up</b>
<i>At risk / Prodromal psychosis</i>							
O'Brien et al., (2014) & Miklowitz et al., (2014) USA	129	RCT	'At risk' young people (mean age 17.4 yrs)	Single family: Psychoeducation, Communication skills, Problem-solving	18 sessions over 6m	Enhanced Standard Care (including 3 psychoeducation sessions)	None
<i>Early Psychosis</i>							
Browning et al., (2013) UK	30	RCT	Inpatients under 18 yrs, psychotic symptoms on admission	Single family: Psychoeducation, Communication skills	5hr sessions over 4–10 wks	(i) CBT (ii) Standard Care	None
Calvo et al., (2014) Spain	55	RCT	Adolescents (14 -18 yrs) with early onset psychosis. Max previous hosp admissions = 3	Single family and Group: Psychoeducation, Problem-solving	3 x 50-min individual sessions, then 12 x 90-min group sessions, bi-monthly, 6m	Non-structured group intervention plus standard care	None
Cozolino et al., (1988) USA	29	RCT (stratified for High/Low EE)	Recent onset of psychosis lasting at least 2 weeks. First episode within 2 years of project entry	Group: Psychoeducation	One-off 3hr session	Standard care	2m

De Giacomo et al., (1997) <i>Italy</i>	38	RCT	Schizophrenia; duration of less than 3 years	Single family: Systemic Family Therapy	10 sessions, weekly	Pharmacological treatment	6m, 12m
Gleeson et al., (2010) <i>Australia</i>	63	RCT (From a larger trial)	First episode psychosis, less than 6 months of prior treatment and remission of positive symptoms	Single family: Psychoeducation, Communication skills, Problem-solving, Relapse prevention	Minimum of 18 months FIp	Enhanced Standard Care	24m, 30m
Goldstein et al., (1978) <i>USA</i>	104	RCT	Early psychosis; all first (69%) and second admissions	Single family: Psychoeducation, Relapse prevention	6 sessions, weekly	Low drug / high drug – Standard Care	6m
Leavey et al., (2004) <i>UK</i>	106	RCT	First episode of psychosis, identified in previous 6 months	Single family: Psychoeducation, Problem-solving, Coping skills	Seven 1hr sessions	Standard care	9m
The Amsterdam Trial: <ul style="list-style-type: none"> <li>• Linszen et al., (1996)</li> <li>• Nugter et al., (1997a)</li> <li>• Nugter et al., (1997b)</li> <li>• Lenoir et al., (2001)</li> <li>• Lenoir et al., (2002)</li> </ul> <i>The Netherlands</i>	76	Controlled longitudinal Design	Recent onset Schizophrenia; 15 - 26 yrs	Single family: Psychoeducation, Communication skills, Problem-solving	18 sessions over 12 months (delivered as flexibly as possible)	Enhanced standard care	12m, 5yr
McCann et al., (2013) <i>Australia</i>	124	RCT	First episode psychosis diagnosis (duration of 2-3 years treatment)	Single family: Problem-solving Bibliotherapy	5 x Bibliotherapy modules, weekly	Enhanced Standard Care	16wk

Rossberg et al., (2010) <i>Norway</i>	301	Cohort analytic	First episode psychosis, actively psychotic and no previous treatment	Group: Psychoeducation, Communication skills, Problem-solving	90 min sessions Bi-monthly over 2 years.	Not offered (e.g. no family) or refused FIp. Standard Care	5 yr
Rund et al., (1994) and Rund et al., (1995) <i>Norway</i>	24	Cohort analytic	Adolescents inpatients (13-18 yrs) with early onset psychosis	Single family and Group: Psychoeducation, problem-solving plus a 'low EE' environment on the inpatient unit	Parent seminars (whole day 2-3 per yr), problem solving sessions, over 2 yrs	Historic Cohort: Patients treated at the same hospital but at an earlier point in time (from 1980 to 1987)	None
Smeerdijk et al., (2014) <i>The Netherlands</i>	72	RCT	Recent-onset schizophrenia (within 5 years) and co-occurring cannabis use.	Group: Family Motivational Interviewing (MI) Skills-training Communication skills. Problem solving using MI	6 x 3 hr sessions, bi-monthly	Standard Care plus Routine Family Support (consultations with family therapist)	None
So et al., (2006) <i>Hong Kong</i>	45	Study 1: wait-list controlled study	Young people (15-25yrs) with first-episode psychosis	Group: Psychoeducation, Skills-training	6 sessions, weekly	Waiting list control plus standard care	6m
Zhang et al., (1994) <i>China</i>	78	RCT	First admission patients with schizophrenia, mean illness duration was 2.8 years, males	Group: Psychoeducation and supportive counselling	Minimum x 1 session once every 3 months for 18 months	Standard care	None

## **Outcomes**

Across the studies, a number of different measures were employed, examining outcomes pertaining to both service users and caregivers. Service user and caregiver outcomes are evaluated separately and studies that assessed multiple outcomes are discussed in each section.

**Service User Outcomes.** Studies presented in this section focused on addressing the extent to which FIp improved outcomes for service users. Nine studies reported outcomes across three main domains: (1) symptoms of psychosis, (2) hospital admissions or relapse and (3) functioning (see Table 5 for summary of significant outcomes).

Table 5  
*The effects of FIp in comparison to control groups for each service user outcome domain*

Primary author	Measures	Service User Outcomes		
		Symptoms	Relapse / Hospitalisation	Functioning
<b><i>At Risk Population</i></b>				
Miklowitz et al., (2014)	SIPS SOPS	✓ (positive attenuated symptoms only)		✓ (Over 19 yrs only)
<b><i>Early Psychosis Population</i></b>				
Browning et al., (2013)	BPRS CGAS Days in hospital	✓? (trend)	×	✓? (trend)
Calvo et al., (2014)	PANSS Relapse: ER visits CGAS	✓	✓	✓
De Giacomo et al., (1997)	BPRS SCOC	✓		✓
Goldstein et al., (1978)	BPRS	✓	✓	
Leavey et al., (2004)	Hospital use: Days in hospital		NS	
Rossberg et al., (2010)	PANSS Relapse: (clinical rating using PANSS scores)	×	×	
Rund et al., (1994, 1995)	Hospital use: number of hospitalisations GAS		✓	✓? (trend)
The Amsterdam Trial:				
• Linszen et al., (1996)	Relapse: clinician rating (based on BPRS rating and clinical notes)		NS × (Low EE)	
• Lenoir et al., (2001)	Hospital use: months in hospital (at 5 years)		✓	NS
Zhang et al., (1994)	BPRS	✓	✓	✓

*Note.* NS = Non-significant findings (no differences between group); ✓ = Statistically significant improvements following FIp; ✓? (trend) = Study reported improvements but not statistically significant; × = Statistically significant negative findings (FIp had an adverse impact). *BPRS* = Brief Psychosis Rating Scale, (C) *GAS* = (Children's) General Assessment Scales, *PANNS* = Positive and Negative symptoms Scales, *SCOC* = Strauss-Carpenter Outcome Scale, *SOPS* = Scale of Prodromal Symptom, *SIPS* = Structured Interview for Prodromal Symptoms; ER = Emergency room

**Symptoms:** Changes in symptomatology were reported in seven studies, one of which measured attenuated symptoms in those deemed at high risk of developing psychosis (Miklowitz et al., 2014). All studies used valid, reliable clinical instruments to assess symptoms. In total, five studies reported statistically significant improvements in positive, negative or attenuated symptoms following FIp in comparison to control groups (Calvo et al., 2014; De Giacomo et al., 1997; Goldstein et al., 1978; Miklowitz et al., 2014; Zhang, 1994). Miklowitz et al., (2014) also noted fewer conversions to psychosis in the FIp group. All studies were RCTs, with moderate to strong EPHPP quality ratings, and showed symptom improvement at the end of treatment, which varied from 6 weeks to 18 months. Gains were maintained at post-treatment follow-up in two studies at 6 and 12 months respectively (Goldstein et al., 1978; Zhang et al., 1994). In addition to these papers, Browning et al., (2013) reported a small effect size ( $d=0.1$ ) for symptom improvement in those with early-onset psychosis (under 18-years old). This was an RCT with a moderate quality rating although had a small sample size (10 participants in each group). In contrast to the other studies, Browning et al., (2013) delivered FIp on an adolescent inpatient unit for the duration of service users' admission, (all other trials primarily delivered FIp when service users were outpatients or a combination of in/outpatient). All the interventions that showed some positive impact following FIp delivered psychoeducation plus at least one other element (primarily problem-solving skills training), the only exception being De Giacomo et al., (1997), which comprised systemic family therapy.

However, in contrast to these six studies, one trial reported significantly *less* improvement in symptoms and a significantly *longer* duration of symptoms following multifamily group therapy than the comparison group, suggesting this may actually have had an adverse effect (Rossberg et al., 2010). In this trial, family intervention was offered bi-monthly over two years to groups of families and service users with post-treatment follow-up at five years. This study was not a RCT, however, the trial involved a large sample (301

service users), received a 'strong' EPHPP rating and offered a manualised intervention to which adherence was closely monitored.

***Relapse and Hospital Admissions.*** Eight studies reported outcomes related to relapse or hospital admissions (Browning et al., 2013; Calvo et al., 2014; Goldstein et al., 1978; Leavey et al., 2004; Linzsen et al., 1994; Lenoir et al., 2002; Rund et al., 1995; Zhang et al., 1994). However there was no consistent measurement criteria used across trials (for example studies used a range of criteria including clinician-rated symptom changes, number of admissions and days in hospital as indicators or measures of relapse). Whilst the various measurement criteria meant it was difficult to compare studies, overall, the findings were mixed. Relapse as defined by number of admissions to hospital and clinician ratings will be examined first, before reporting on less robust measurement criteria such as duration of time in hospital.

**Relapse defined by hospital admissions and/or clinical measures:** Five studies reported relapse outcomes in relation to hospital admissions and/or clinical ratings, and three found a reduction in relapses for the FIp group (Goldstein et al., 1978; Rund et al., 1995; Zhang et al., 1994). However, Rund et al., (1995) compared FIp to an historical cohort, meaning it is possible that other cohort effects (such as changes in mental health care provision over time) could explain reductions in hospital admissions, and not necessarily FIp. Furthermore, Zhang et al., (1994) only examined male service users and thus findings cannot be generalised to females.

Two further studies reporting relapse outcomes found either no effect or a negative effect of FIp on relapse rates. A longitudinal clinical-controlled trial with a moderate to strong EPHPP rating found a reduction in the months spent in hospital at 5 years post-treatment (Lenoir et al., 2001), but reported no overall group differences in number of

relapses at either 12 month follow-up (Linzen et al., 1996), or at five years (Lenoir et al., 2002). They also note that patients from families with Low EE relapsed significantly *more* in the FIp group compared to psychosocial intervention alone (Linzsen et al., 1996). In addition, one further trial reported a negative impact of multi-family group therapy on relapse (Rossberg et al., 2010). This study has been detailed in the section above (with regard to their negative finding on symptoms).

*Days in hospital.* Three studies reported on length of hospital admissions, two of which reported no overall significant differences between groups and one reported an increase in number of days in hospital for those in the FIp group. Calvo et al., (2014) noted reduced visits to the emergency department but no differences in the number of days service users were hospitalised (although sample size at follow-up was small). One RCT (Leavey et al., 2004) found no differences in the number of days spent in hospital. However this study reported a low intervention take-up (only 53.5% participated following initial invitation) and low treatment completion: the majority (58%) only partially completed the intervention. In a separate study, Browning et al., (2013) examined an under-18 population and found the family therapy group had an increased length of stay in hospital compared to standard care. However, this study involved a small sample and variability was high.

*Functioning:* General functioning was measured across studies using the Children's/Global Assessment Scales (CGAS, Shaffer, Gould, Brasic et al., 1983; GAS, Endicott, Spitzer, Fleiss et al., 1976) or Strauss-Carpenter Outcome Scale (SCOS, Strauss & Carpenter, 1972). Of the seven studies reporting outcomes related to patient functioning, three noted statistically significant improvements following FIp (Calvo et al., 2014; De Giacomo et al, 1997 & Zhang et al., 1994). Of these, one found that differences were confined to those service users who had not relapsed during the trial (i.e. participants in the

FIP arm who were not readmitted had higher levels of functioning post-intervention than controls who were not readmitted; Zhang et al., 1994). All three studies reporting improvements were RCTs, had active comparison groups and were rated as moderate to strong on the EPHPP. A further two studies supported trends for improvement in functioning (Rund et al., 1994 & Browning et al., 2013). Browning et al., (2013) had a small sample but showed promising effect size for improved functioning ( $d=0.4$ ).

In addition to these studies, Miklowitz et al., (2014) provided some support for improved psychosocial function following FIP. The sample as a whole demonstrated improved function over time, but changes between FIP and the comparison group (enhanced care) depended on age: participants over 19 years of age improved more following FIP, whereas participants between 16 and 19 years of age improved more in the comparison group (which included three family psychoeducation sessions). However, one study reported that over the course of five years there was no difference in functioning for those who received FIP (Lenoir et al., 2001).

***Summary of Service User Outcomes.*** Overall, five of the seven studies (71%) reported that FIP resulted in improvement in service user symptoms during the treatment period and up to one year post-treatment, including one study referring to an at risk group. This review provided no evidence FIP reduced relapse in the early psychosis and moreover, could potentially be harmful in low EE families and for those with early onset psychosis. There was, however, some evidence demonstrating improved service user functioning.

**Carers Outcomes.** Out of the 15 studies, 10 reported outcomes for carers relating to four main areas: (1) expressed emotion or 'family environment', (2) communication, (3) experiences of caregiving and (4) general health (see Table 6 for summary of outcomes).

Table 6  
*The effects of FIp in comparison to control groups for each caregiver outcome domain*

Primary author	Measures	Caregiver Outcomes			
		Expressed Emotion (EE)	Communication	Caregiving experiences	Health
<b><i>At Risk Population</i></b>					
O'Brien et al., (2014b)	Behavioural observation ratings		✓		
<b><i>Early Psychosis Population</i></b>					
Calvo et al., (2014)	FES	NS			
Cozolino et al., (1988)	FCS PRS	NS	NS		
De Giacomo et al., (1997)	FMSS	✓? (trend)			
Gleeson et al., (2010)	FQ GHQ	NS		✓	NS
McCann et al., (2013)	FMSS	NS		✓	NS
Rund et al., (1994) and Rund et al., (1995)	FIp: CFI Control: clinical rating	✓	NS		
Smeerdijk et al., (2014)	Empathy		✓		
So et al., (2006)	LEE ECI CWCQ	NS		✓? (trend)	
The Amsterdam Trial:					
• Nugter et al., (1997)	TAT		NS		
• Lenoir et al., (2002)	FMSS	✓ (34 months) NS (60 months)			

Note. NS = Non-significant findings (no differences between group); ✓ = Statistically significant improvements following FIp; ✓? (trend) = Study reported improvements but not statistically significant; ✗ = Statistically significant negative findings (FIp had an adverse impact). CD = Communication Deviance, CWCQ = Chinese wellbeing and coping Questionnaire, ECI = Experience of Caregiving Questionnaire, FCS = family conflict scale, FES = Family Environment Scale, FMSS = Five Minute Speech Sample, FQ = Family Questionnaire, GHQ = General health questionnaires, LEE = Levels of Expressed Emotion, PRS = Patient Rejection Scale, TAT = Thematic Apperception Test

***Expressed Emotion.*** Eight studies measured outcomes related to EE. Reducing high EE is often a principle aim of FI, however only one trial showed change in the desired direction, one did not state significance levels and six reported no significant differences between FI and controls. Rund et al., (1994) found that post-intervention, 84% of FI families changed from high to low EE, while none of the families in the control group changed. However, *all* caregivers in both groups were rated as high EE at the beginning of treatment (higher than the proportion found in other studies which is around 50% of the sample). Furthermore, the study received a weak rating (EPHPP), as the comparison group was an historical cohort and the outcome measures used to assess EE differed between experimental and control groups (the Camberwell Family Interview was used for the experimental group and a 'retrospective clinical rating' following examination of case notes was used for the comparison group). This means the outcome assessment for the control group was not reliable, and the assessors were not blind. These measurement differences confound the meaning of the results and conclusions cannot be drawn from this study regarding group differences and EE. In addition to this study, De Giacomo et al., (1997) found four out of nineteen cases in the FI group changed from High to Low EE, while none of the patients in the comparison group (pharmacological treatment) showed a similar change, however it is not stated whether this difference was statistically significant.

The remaining six studies found no differences in EE between the groups (Calvo et al., 2014; Cozolino et al., 1988; Gleeson et al., 2010; Lenoir et al., 2002; McCann et al., 2010; So et al., 2006). Whilst one study noted fewer critical comments in the FI group following a 6-week intervention, these differences were not maintained at 16 weeks (McCann et al., 2010). Linzsen et al., (1996) indicated FI may reduce levels of EOI, but again only for a limited period. They also comment that it was more difficult to engage the Low EE families in the intervention. Across all six trials reporting non-significant findings, the quality varied, with one trial rated as weak due to a particularly high dropout rate and differences between groups that were not controlled for (Gleeson et al., 2010).

*Communication.* A principal aim of those interventions based on problem-solving is to improve communication within families, with the further aim of reducing stress. A total of five studies reported on changes in communication. Two studies examined changes in Communication Deviance (the degree to which a speaker and listener are able to establish and maintain shared focus of attention during interaction) and one study looked at levels of ‘family conflict’. None of these found any effect of FIp on communication styles (Cozolino et al., 1988; Nugter et al., 1997; Rund et al., 1995). However, in two of these studies, there was likely a mismatch between the aims of the intervention and the outcome measures; the interventions offered did not specifically intend to change communication style (Cozolino et al., 1988; Rund et al., 1995). Further, in Nugter et al., (1997), whilst improving communication skills was a target focus of the intervention, the authors note that the outcomes measured did not directly assess the constructs that the intervention was aiming to change.

There were two studies that reported significant improvements in communication style following FIp. O'Brien et al., (2014) showed improvement from baseline to 6-months in constructive communication (active listening and calm behaviours) and decreases in conflictual behaviours during family interactions compared to those in enhanced care. This study looked at those at risk of developing psychosis and offered a time-limited (six-month) intervention specifically designed to improve communication. This was a moderate RCT with a good sample size and it may be that this trial examined outcomes that more accurately reflected what the intervention was trying to change. In addition, Smeerdijk et al., (2014), rated as a strong study, found greater expressions of empathy following FIp.

*Caregiving Experiences.* Caregiving experiences were examined in three studies, all of which found some improvement in at least one aspect of caregiving following FIp. All studies used the Experience of Caregiving Inventory (ECI, Szmukler et al., 1996) which

measures caregivers' subjective experiences related to two main domains: positive and negative. In Gleeson et al., (2010) the FIp group showed larger reductions in negative experiences, in addition to increased positive experiences compared to controls, although this study had a high drop-out rate. McCann et al., (2013) also found that the group receiving bibliotherapy reported a more favourable experience of caregiving, an effect which was maintained at 16 weeks. So et al., (2006) found no significant results on the full-scale of this measure but reported reduced 'problems with services'. These trials were all RCTs, differing in terms of intervention content and duration; however they all offered a problem-solving component.

**Health.** Two studies measured outcomes related to health, neither of which reported any effect following FIp at 16 week post-treatment follow up (McCann et al., (2013) or over three years (Gleeson et al., 2010).

**Summary of Caregiver Outcomes.** Overall, there was no evidence that FIp reduced levels of EE and there was some indication that it may be harmful for low EE families. There was also no evidence for changes in familial communication styles or caregivers' health, however there was some indication that FIp may improve caregiving experiences.

## **Discussion**

### **Summary of Results**

This systematic review aimed to answer key questions about the efficacy of family interventions in early psychosis and their outcomes for service users and relatives. All

studies examined FIp as an adjunct to standard care and/or pharmacological treatment in comparison to a control group (primarily standard care alone). The review yielded 21 papers from 15 distinct trials and revealed mixed results. Overall, the findings of this review suggest FIp may have an important role in reducing patient symptoms and increasing general functioning for those with early psychosis. However, the evidence for reducing relapse rates or hospital admissions was equivocal. Furthermore, there were two key groups for whom caution is advised when offering FIp: individuals with early-onset psychosis (onset under the age of 18 years) and families with low EE. There was no evidence for change in the family environment (including levels of EE and communication) or caregivers' general health. Limited evidence suggested that FIp improved caregiving experiences; however as very few studies reported on this outcome, this finding should be interpreted with caution.

**Service User Outcomes.** This review showed that FIp may be effective for reducing positive and negative symptoms of psychosis for individuals in the early stages of the illness and that these improvements may be sustained after one year. There were also promising trends for increased patient functioning and both these findings replicate the literature examining FIp in mixed-duration schizophrenia-spectrum disorders (e.g. Pharoah et al., 2010). It is of note, however, that a multi-family group intervention appeared to have a negative impact on symptoms (Rossberg et al., 2010). It has been suggested that group interventions may not be beneficial for carers of those with severe mental illness due to individual differences such as chronicity of symptoms and length of illness (Haahr et al., 2012). However, a number of other studies in this review also offered interventions to groups of families and reported a variety of positive or equivocal findings related to a number of different outcomes another study in the review. One study in particular (Zhang et al., 1994) offered a similar group intervention to families and service users and found symptom improvement, suggesting that groups *per se* are not necessarily problematic or adverse for this population. Inspection of the group interventions offered in these other trials

revealed that they generally provided a single-family element in addition to the multi-family groups or clustered families with similar difficulties in the same group (for example those experience co-occurring cannabis use). This was in contrast to Rossberg et al., (2010) who offered a multi-family intervention with no individual tailoring. Qualitative feedback from early psychosis carers indicates multi-family groups are experienced as helpful and supportive but they needed to be tailored to individual families' needs (Sin, Moone & Wellman, 2005). To improve the efficacy of multi-family group interventions, individual needs and grouping arrangements should be carefully considered, taking into account those who share similar difficulties or chronicity, rather than a 'one-size fits all' approach.

Increased hospital admissions and a greater number of relapses in psychosis are associated with poor prognosis, increased personal and familial distress (Ho et al., 2003), as well as disrupted social and vocational development in young people (Penn et al., 2005). Preventing or reducing relapse is therefore an important goal of FIp. Unlike reviews of the broader schizophrenia-spectrum (Pharoah et al., 2010) and in contrast to a previous review examining early psychosis (Bird et al., 2010), the current review did not find evidence for FIp reducing hospital admissions, relapses or days in hospital. This finding may be due to methodological issues in the reviewed studies, for example predominantly short follow-up periods may mean relapse may not be fully known at the post-test stage. Furthermore, this review included studies without a randomised-controlled design, meaning that unknown confounders may have influenced the results. Alternatively however, in the early stages of psychosis, caregivers' understanding of psychosis and the manner in which they relate to their relative may still be evolving, therefore the efficacy of FIp in this stage may be less stable.

Whilst the studies in this review principally found no significant difference between FIp and controls in rates of relapse, there were two groups for whom FIp appeared to increase relapse risk or length of hospital admission: those with low EE families (which will be addressed in the section discussing caregiver outcomes) and those with early-onset

psychosis (those under 18 years of age). Overall, the findings regarding the early-onset group are inconclusive in this review; however there are indications that some types of FIp at this stage may be unhelpful, with one study reporting a longer duration in hospital for this age group following FIp (Browning et al., 2013). In addition, Miklowitz et al., (2014) found that 16-19 year old who were at risk of developing psychosis showed greater improvements in general functioning in the control group (consisting of three family psychoeducation sessions) compared to the FIp group (18 sessions of family-focussed therapy).

Those with early-onset psychosis often have greater pre-morbid impairments compared to those with later-onset (over the age of 18), including social impairments, lower cognitive function, and delays in language and reading (Hollis, 2003). They have been shown to be a distinct group with a much higher risk of adverse outcomes (Diaz-Caneja et al., 2015; Ropcke & Eggers, 2005; Schimmelmann, Conus, Cotton, McGorry & Lambert, 2007). As such, it has been noted that family interventions offered to this group need to be highly adapted to be effective (Sin, Moone & Newell, 2007). Incorporating themes that are particularly relevant for the families of young people in this age group such as cannabis and alcohol use may also be of benefit (Sin et al., 2007). Further proposed modifications include altering language from 'relapse prevention' to 'working towards recovery', noting that many carers are only beginning to accept the first episode of acute mental illness in their young relative, and many have not yet considered that it may reoccur in the future (Sin et al., 2007). Caregivers themselves are likely to have different pressures, for example managing wide professional networks to ensure continuity of education (Boeing et al., 2007). In addition, there are often limited inpatient provisions for this age group (Boeing et al, 2007), which may mean that families are required to travel some distance to visit their relative, should an admission be required. The different needs in the early-onset group may mean that offering generic family interventions could be unhelpful at this stage. Although specialist intervention services for the early stages of psychosis have been developed (International Clinical Practice Guidelines for Early Psychosis, 2005), these generally offer a similar

service to all those aged 14-35 years old. It may be that those who develop psychosis under the age of 18 years old require further adaptations, with age-specific interventions.

**Caregiver Outcomes.** The evidence documenting the positive impact of FIp for carer outcomes was limited. This review found no evidence that FIp reduces high EE within an early psychosis sample, including at five-year follow-up (Lenoir et al., 2002). This is in contrast to the broader schizophrenia-spectrum literature, where it has been suggested that FIp may improve levels of EE (Pharoah et al., 2010). However, Birchwood and Smith (1987) proposed that EE is not a trait characteristic, rather the emerging illness along with patient and caregiver characteristics may contribute to caregiving responses, behaviours and attitudes. Early psychosis is characterised by high levels of carer and patient distress and fluctuating symptoms, which may contribute to EE being particularly unstable, changing over time or in relation to stressors rather than intervention. Symptom severity or duration were not typically controlled for across the studies, thus limiting the conclusions that can be made in this regard. Future work is needed to understand the mechanisms of EE in order to prevent the entrenchment of high EE behaviours and responses in the long-term. It is likely that until we understand these mechanisms, current interventions for the early psychosis group may be limited in their effectiveness. One aspect of the family environment that was not measured in the current studies, but may benefit from future research was warmth. If FIp improved caregivers' experiences, this may impact on aspects of the family environment not captured by current measures (for example an increase in positive regard e.g. Berglund, Vahlne & Edman, 2003).

Furthermore, one study indicated that caution should be exercised in offering FIp (specifically communication training and problem-solving) to low EE families. The authors highlight that offering interventions such as communication training when this is not a problematic area for a family may be perceived as invalidating and critical, thus increasing

stress and adversely affecting relapse (Linszen et al., 1996). It is important to recognise that not all families will require intervention, in fact some families (for example those with low EE) may be harmed by FIp. In addition, Bhugra and McKenzie (2003) reviewed the cross cultural literature on EE and noted some families view FIp as somewhat intrusive and prescriptive, whereas others find it a useful way to learn more about supporting their relative through the illness. It may be important to fully assess caregivers needs and wishes before offering FIp.

Additionally, this review found no evidence for improvements in caregiver psychological health or general well-being. It is known that carers of individuals with early psychosis experience high levels of distress and related health problems (Addington, Coldham, Jones, Ko & Addington, 2003; Tennakoon et al., 2000). In their large-scale, qualitative investigation of 80 early psychosis carers, Lavis et al., (2015) noted that carers of people with early psychosis describe an ongoing level of distress and a continual adjustment process. They suggest that the distress can remain long after the service user recovers, as carergivers' lives have often been greatly impacted by the first experience of psychosis in the family. Consequently, measuring distress at only two points in time may not reveal significant change. Lavis et al., (2015) also note that carers often reported they were not asked by the service about how they themselves were managing and feeling. The lack of improvement in outcomes related to caregivers' health indicates the need for specific assessment and intervention to ensure carers' needs are adequately met. It is possible that early intervention services and family interventions are effective in providing information about psychosis and practical issues (such as medication management) but more needs to be done to address carers' own levels of personal distress and the emotional experience of caregiving, which may serve to improve health-related outcomes in the future (Lavis et al., 2015).

The only outcome to show positive change for carers was that of caregiving experiences. Whilst only a limited number of studies reported on this outcome, they

provided some evidence that FIp improves the appraisal of caregiving, with studies observing reductions in negative experiences and increases in positive experiences. These findings replicate other studies examining the wider schizophrenia spectrum (Giron et al., 2010). It could be argued that FIp allows families to feel more supported in their caregiving experiences which in turn impacts on their subjective appraisals of caregiving. Qualitative research suggests that carers of people with early psychosis find components of FIp such as information around psychosis and medication management important in helping to increase their confidence in supporting their relative (Lavis et al., 2015).

## **Limitations**

**Heterogeneity amongst included studies.** The diversity of characteristics in the included trials limits the conclusions that can be drawn. There were differences with regard to patient characteristics (including age of symptom onset, duration of untreated illness and baseline symptom severity) alongside differences in the characteristics and components of the interventions (which varied in content, structure and duration). This restricts the conclusions that can be drawn about the specific components of FIp that might be most effective for whom. Furthermore, the nature of comparison groups was highly variable. Nearly half the trials examined in this review described specialist early intervention for psychosis services as standard care (Calvo, 2014; Gleeson, 2010; Linszen, 1994; McCann, 2013; O'Brien & Miklowitz, 2014; Rossberg, 2010). These generally comprised set treatment protocols including optimal pharmacotherapy and a range of psychoeducational and psychosocial interventions, often including individual psychotherapy if required. This may mean that some effects of FIp are concealed. For example, one study did not find differences between groups, but noted both FIp and the standard care control groups demonstrated lower relapse rates in comparison to those found in the wider literature (Linszen et al., 1996). They suggest that the highly specialist nature of the service is likely to have been an effective intervention in its own right, thus making it difficult to demonstrate

any further benefit of FIp. It may be that shared components of FIp and specialist care (such as regular contact with a team) allow a family to feel supported more generally.

Alternatively, there may be similar outcomes but different mechanisms for change. For example, FIp may improve symptoms via warmth and problem-solving, whereas specialist services improve symptoms via medication management and/or contact with care coordinators.

In addition, due to the ethics related to withholding effective treatment, some studies offered a limited number of family psychoeducational sessions in control conditions, which again might mean the full impact of FIp is underestimated in these studies. Conversely, it was not possible for the comparison groups to control for non-specific factors such as the number of face-to-face contacts or being in a group. For example, there is evidence that support groups have been shown to be particularly beneficial for carers of people with early psychosis (Chien & Norman, 2009). Further research is needed to determine the active ingredients of FIp.

**Carer engagement with treatment.** Poor intervention uptake and high dropout rates were a feature of some trials, particularly those that included longer follow-up periods. There are likely to be significant differences between those who engage in treatment and follow-up and those who drop out, thus potentially biasing the results in the included trials. For example, Nugter et al., (1997) noted that the families who completed treatment were generally a well-functioning group who had engaged throughout, which may have meant there was little room for further improvement to be captured. There is a limited understanding of the variables that may influence the engagement of carers with services. It is important to understand the barriers to engagement and identify the specific needs of early psychosis families to determine the factors that may help promote better engagement with services when they are required.

**Methodological considerations.** This review adhered to the PRISMA (Liberati et al., 1999) guidelines and to many principles of the Cochrane Collaboration in order to develop a thorough search strategy. However, it should be noted that meta-analyses are considered the ‘gold standard’ for reviewing the literature and are less prone to bias (Teagarden, 1989). They are indicated when comparing studies with few treatment differences and similar procedures. Meta-analysis was deemed inappropriate for this review, as there was great heterogeneity in study design and treatment, including differences in the type of intervention offered, the comparison group examined, the intervention duration and standard care offered by services. It is important that future research measures and records outcomes in a consistent manner required for effective future meta-analysis.

### **Clinical Implications and Future Research**

We cannot make specific recommendations regarding the optimal components of FIp for early psychosis, given the heterogeneity of included trials and the specific focus of this review on caregiver and patient outcomes (rather than the intervention components). However, preliminary findings suggest that multifamily group therapy should not be offered unless this is tailored to families, for example by selecting families with similar difficulties to work together. In addition, further research is required to understand the type of FIp, if any, that is most effective for those with early-onset psychosis and those from low EE families.

The high treatment dropout rates and lack of significant improvement in caregiver outcomes, indicates a need to develop interventions that are more favourable for carers. In order to increase engagement, it will be important to adapt interventions to more closely match caregivers’ needs. Leavey et al., (2001) noted that at the very early stages, carers requested more practical support, such as details on welfare benefits or how to access services. It may be pertinent to offer this before moving on to problem-solving, relapse-

prevention and skills-based training - if required - later on. It has been suggested that carers know 'how much' they need, rather than interventions being prescribed for them (Leavey et al., 2004) and that families might adjust their involvement with services and interventions in line with the intensity of symptoms (Gleeson et al., 2010). It may be important to develop services for carers that are more carer-informed and carer-led, rather than assuming generic protocols (Sin et al., 2007). In line with the recommendation in Onwumere et al., (2011) it may be helpful for early intervention services to adopt a triage system to assess relatives' needs and to have a range of flexible interventions available, including low-intensity approaches such as information leaflets alongside more intensive and therapeutic family support options.

Furthermore, ensuring services are more culturally sensitive may further improve engagement. Qualitative research indicates that Early Intervention for Psychosis services need to go further in addressing cultural, religious and spiritual beliefs early on in the assessment process, incorporating this understanding into ongoing treatment. They note that factors such as caregivers' previous models and explanations of mental illness are not typically incorporated into service delivery. For example many people have religious and spiritual explanations for mental illness, which influence how they might understand and respond to psychosis. Such factors need to be considered on an individual basis along with collaborative work with local faith leaders (Islam, Rabiee & Singh, 2015).

In addition, Internet-based therapy and bibliotherapy deserve further exploration. Only one study utilised bibliotherapy (McCann et al., 2013) and described a high retention rate, which may reflect the fact that carers were able to complete the programme at a time and place of their own convenience. It is also a cost and time effective intervention which may seem less intrusive than attending clinics, thus helping to minimise potential stigma experienced as a consequence of attending mental health services. Further understanding of caregiver adaptation to the onset of psychosis in a loved one is required alongside ascertaining the type of intervention and active ingredients that are most effective for whom.

Such research can then inform the development of theoretically driven yet tailored interventions.

## **Conclusions**

FIP generally aims to increase familial understanding of relapse indicators, helping relatives to engage in supportive patterns of responding, thus preventing relapse and readmission (Onwumere et al., 2011). However, the mixed results in this review, and the limited improvement in caregiver outcomes, means it is hard to determine the pathway by which FIP improves patient outcomes. It is possible that FIP helps carers support their family members more by providing information and guidance on the practical tasks and assisting with medication management. Evidence suggests that carers' own needs and the emotional impact of caregiving may be a neglected area of FIP and could account for the limited improvement in caregiver outcomes. Further research is now required to develop interventions that meet the specific needs of caregivers of early psychosis. Research would also benefit from increased coherence between intervention content and measurement outcomes.

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## **Part Two: Empirical Paper**

### **Can Caregiving Experiences be Understood Using an Attachment Framework in Early Psychosis?**

## **Abstract**

**BACKGROUND:** High expressed emotion (EE) has been shown to be a robust predictor of poorer outcomes for people with psychosis and is associated with negative caregiving experiences such as caregiver distress. However, empirical evidence has some way to go in understanding the key factors and mechanisms that influence the development of high EE.

**AIMS:** The present study aims to examine the role of caregiver attachment in early psychosis, considering the relationship between insecure attachment style and high EE together with an examination of the role of attachment in caregiving variables traditionally associated with high EE.

**METHOD:** A cross-sectional design was employed. Carers of people experiencing early psychosis completed a series of measures assessing EE, adult attachment style, beliefs about illness, experiences of caregiving and levels of distress.

**RESULTS:** Forty caregiving relationship sets were examined. Those carers who were observer-rated as high and low EE did not differ on their attachment style, but self-reported levels of emotional over-involvement were associated with a fearful-avoidant attachment style. Moreover, the influence of fearful-avoidant attachment on both overall caregiver distress and the emotional impact of illness was found to be mediated by emotionally over-involved behaviours.

**CONCLUSION:** This study offers tentative support for the role of attachment in understanding caregiving responses. Attachment theory may offer important contributions to understanding the influences and origins of expressed emotion as well as further insight regarding caregiving responses such as distress.

## **Introduction**

Psychosis is characterised by distortions of thought and perception, resulting in an altered sense of external reality (World Health Organisation, 1992). The distinctive features of psychosis, such as hearing voices, can be a frightening and overwhelming experience for the person involved and those around them. Caring for an individual with psychosis places significant strain on family members and many report feeling under-resourced to manage the challenges that can accompany this role (Tan et al., 2012). The process of caregiving is associated with high levels of distress (Kuipers et al., 2006) and as many as 30% of carers report trauma-like symptoms (Barton & Jackson, 2008; Loughland et al., 2009).

The first episode of psychosis usually occurs in adolescence (Mueser & McGurk, 2004) with the five years following the emergence of symptoms considered to be a ‘critical period’; determining the future course and prognosis of the illness and offering a window for ensuring optimal support and treatment (Birchwood, McGorry & Jackson 1997). The manner in which family members respond, particularly in the early stages, has considerable influence over long-term service user outcomes (Bebbington & Kuipers, 1994; Butzlaff & Hooley, 1998).

## **Expressed Emotion**

The construct of expressed emotion (EE) provides a quantifiable measure of the family environment and interpersonal relationships (Brown, 1959, 1985; Butzlaff & Hooley, 1998). EE largely refers to the thoughts and behaviours expressed by a carer about the person with psychosis. EE comprises five dimensions, namely: critical comments, hostile tone, emotional over-involvement (EOI, conceptualised as the tendency to be intrusive or over-protective), warmth and positive regard (Wearden, Tarrier, Barrowclough, Zastowny & Rahill, 2000). EE is generally assessed by interview measures such as the Camberwell Family Interview (Leff & Vaughn, 1985) or the Five Minute Speech Sample (Magana et al., 1986). Carers are typically categorised as high EE if they score above threshold levels on

any (or all) of the criticism, hostility or EOI scales (Leff & Vaughn, 1985; Vaughn & Leff, 1976). Low EE carers are rated as such since they have not scored above threshold.

The influence of familial EE on the course of psychosis and schizophrenia is well established (Amaresha & Venkatasubramanian, 2012). High EE is a robust predictor for increased relapse, longer hospital admissions and poorer outcomes for people with schizophrenia-related conditions (Butzlaff & Hooley, 1998; Wearden et al., 2000), with criticism recognised as the most predictive of the EE scales (Cechnikki et al., 2014). High EE is also linked to higher carer burden, distress, depression and negative caregiving experiences (Barrowclough & Hooley, 2003; Raune, Kuipers & Bebbington, 2004; Kuipers et al., 2006).

Whilst the predictive validity of EE is well established, the ways in which EE responses develop and are maintained together with the mechanisms by which EE influences service user and caregiver outcomes are largely unknown (Berry, Barrowclough & Wearden, 2007). Some associations have been found between symptom severity and caregiving responses (Tuker, Barker & Gregorie, 1998; Tennakoon et al., 2000), however the similarity in illness-related variables (e.g. symptoms) across high and low EE families suggests that the variance in EE is, at least in part, due to reasons beyond those related to the illness (Leff & Vaughn, 1985; Kuipers et al., 2006; Raune et al., 2004; Addington, Coldham, Jones, Ko & Addington, 2003; Leff, 1976).

Attribution models (Hooley, 1985, 1987) have highlighted the importance of the carers' appraisals in understanding the development of EE; for example, caregivers who believe that the service user has control over symptoms show increased critical comments (Barrowclough & Parle, 1997; Barrowclough, Johnston, Tarrier, 1999; Barrowclough & Hooley 2003). In addition to appraisals about controllability, two further illness appraisals have been identified as playing an important role in high EE: timeline (carers who perceive the illness as long-term are more likely to display high EE) and consequences (the greater

the subjective impact of the illness on the caregiver, the higher levels of EE displayed; Barrowclough, Lobban, Hatton & Quin, 2001; Lobban, Barrowclough & Jones, 2005; Lobban, Barrowclough & Jones 2006; Kuipers et al., 2007). Furthermore, negative appraisals are associated with higher levels of distress in caregivers (Lazarus & Folkman, 1984; Onwumere, et al., 2008). However, understanding remains limited with regard to the psychological factors that may underlie these appraisals and thus influence levels of EE.

### **A Model of Caregiving**

The caregiving experience is complex and multifaceted, influenced by both internal psychological processes as well as external factors (Jansen et al., 2014a). Kuipers and colleagues proposed a cognitive model of caregiving responses in psychosis, outlining pathways for three primary responses to develop: positive, over-involved or critical/hostile (Kuipers, Onwumere & Bebbington 2010). Crucially, this model suggests caregiving responses are dependent upon the quality of the relationship between the carer and service user *prior to* an episode of psychosis, which influences initial illness appraisals and subsequent caregiving behaviours. This model is a useful framework for understanding processes involved in caregiving but the authors highlight the need for further research, particularly the need to investigate what constitutes ‘quality’ in the initial relationship and the factors that contribute to the development of initial appraisals. It has been suggested that attachment theory (Bowlby, 1969, 1982) may be a useful framework for understanding caregiving processes and EE in early psychosis (Berry et al., 2008a; Patterson, Birchwood & Cochrane, 2005).

### **Attachment Theory and Caregiving**

Attachment theory has shaped the way interpersonal relationships are understood across the lifespan (Bowlby, 1973). The first attachment bonds are formed with primary

caregivers and these early experiences serve as the template for later relationships (Bowlby, 1969). Infants internalise their experience of being cared for which leads to the development of internal representations (or working models) of 'self' and 'others' (Bowlby, 1973). Specifically, the sensitivity of the caregiver influences the extent to which the cared for individual believes they are worthy of love and care, and the extent they trust other people are dependable and responsive (Main, Kaplan, & Cassidy, 1985). These working models are the hypothesised mechanism that transfers attachment behaviours to different relationships, thus form the foundation for understanding how early caregiving experiences influence relationships throughout life (Bowlby, 1979; Pietromonaco & Barrett, 2000). Based on Bowlby's (1973) model of self and others, a two-dimensional construct of adult attachment was proposed (Bartholomew & Horowitz, 1991; Griffin & Bartholomew, 1994). A prototypical *Secure* attachment is characterised by a positive view of self and others. A *preoccupied-Anxious* attachment is characterised by a negative view of self but a positive view of others, leading to a sense of self-worth dependent upon gaining the approval of others. There are two insecure-avoidant styles: *Fearful-Avoidant*, characterised by a negative self-image combined with fear that others cannot be trusted to be loving and available; and *Dismissing-Avoidant*, a positive self-image, combined with a negative expectation of significant others as demanding, leading to the dismissal or avoidance of close relationships. These attachment scripts serve as the foundation for care-seeking and care-giving behaviour, influencing the sensitivity of a caregiver to a care recipient and guiding patterns of caregiving interactions (Bowlby, 1982, 1982; Collins, 1996; George & Solomon, 1999; Kuncze & Shaver, 1994).

Attachment theory is not framed as a general relationship theory; rather it seeks to explain how people respond within a relationship context when hurt, separated from loved ones, or faced with a perceived threat (Bowlby, 1973; 1980; Waters, Merrick, Trebour, Crowell & Albersheim, 2000). Given this context, the relevance of attachment theory to caregiving – a response which commonly takes place when people are faced with a potential

threat to the established relationship equilibrium and possible separation from a loved one - is increasingly recognised. To date, caregiver attachment style has predominantly been examined with regard to sensitivity in adult romantic caregiving relationships (Hazen & Shaver, 1987; Simpson, Rholes & Nelligan, 1992) and parental caregiving, including amongst children with mental illness (Farinelli & Guerrero, 2011). Insecure attachment styles are related to less sensitive and less responsive caregiving in addition to increased symptoms of depression in carers (Farinelli & Guerrero, 2011). Research has also shown that insecure attachment is associated with critical or over-involved parenting styles in young adolescents with severe mental health difficulties (Diamond & Doane, 1994). More recently, associations have been found between insecure attachment and 'psychological mindedness' (the extent one is able to understand problems to be the result of psychological difficulties) in professional caregiving relationships within early psychosis (Berry et al., 2008b).

### **Attachment Theory and Caregiving Experiences in Early Psychosis**

**Expressed Emotion.** Attachment theory and expressed emotion both examine the quality of interpersonal relationships, however little is known about the association between these two constructs. Previously conceptualised as a sign of 'family dysfunction' (as discussed in Jansen et al., 2014a), there is increasing support that High EE may be an attempt to show care, recognising that some High EE behaviours are understandable ways of responding to and coping with stressful situations (Jansen et al, 2014a; van Os et al., 2001). For example, critical responses to distress could be activated through the attachment system as a way of ensuring the safety of an individual, expressing concern and modifying their behaviour (as suggested by Bowlby; 1980, 1982). Criticism within the context of caregiving in early psychosis may be a coping strategy to deal with the experience of perceived loss in the same way a mother, driven by fear of loss, might be very critical and shout at her child if they attempted to run into a busy road (Barrowclough & Tarrier, 1992). Furthermore, when

faced with a potential stressor, individuals with an anxious attachment style display increased proximity-seeking behaviours, such as those characteristic of EOI behaviours (Dewitte, Houwer, Buysse & Koster, 2008). One study examined the influence of childhood experiences in caregivers of people with schizophrenia and found a relationship between caregivers' subjective reports of overprotection from their own parents and the degree of EOI expressed in the current caregiving role (Paley, Shapiro, Worrall-Davies, 2000).

**Caregiving Responses.** Attachment theory may also inform our understanding of the different caregiving variables that have been commonly associated with High EE (e.g. negative caregiving experiences and distress). Insecure attachment style has been associated with increased self-reported negative caregiving experiences (burden) in adult caregivers of people with dementia (Crispi, Schiaffino & Berman, 1997). In addition, individuals with insecure attachment styles tend to use more avoidant and maladaptive coping styles, which have been further associated with increased distress (Lopez, Mauricio, Gormley, Simko, & Berger, 2001). Patterson et al., (2005), suggested that the attachment style of the carer may influence the development of cognitive biases, which in turn may guide appraisals made about the illness along with caregiving behaviours and subsequent distress. Berry, et al., (2007, 2008a), propose that further work is needed in this area in order to understand the extent to which caregivers' own attachment security may influence critical or EOI responses.

### **Rationale for this Study**

It is known that the family environment and caregivers play an important role in the course and recovery of an individual with psychosis (Bebbington & Kuipers, 1994). The current study aims to explore the contribution of attachment theory to caregiving in early psychosis by examining the relationship between caregiver adult attachment style and the quality of the caregiving relationship as measured by EE and key related caregiving variables. Under acute levels of stress experienced during early psychosis, caregiving

attachment-based scripts may become activated, which may in turn influence caregiving appraisals, patterns of expressed emotion and related caregiving responses (such as distress). EE behaviours could mediate a relationship between insecure attachment and the established caregiving responses. An early psychosis sample has been chosen due to evidence indicating this is a critical point for intervention, shaping long-term outcomes (Birchwood et al., 1997). Examining EE in the early stage of psychosis also allows for increased understanding of its origins, which can guide the development of interventions to prevent longer-term entrenchment (Raune et al., 2004).

## **Hypotheses**

To the author's knowledge there is no previous research measuring caregiver attachment style and expressed emotion in early psychosis, thus the present study has a number of exploratory hypotheses:

- 1) Insecure attachment style will be associated with high EE (EOI and Criticism)
- 2) Replicating findings in the empirical literature, high EE will be associated with the following caregiving variables: increased distress, negative care-giving experiences, and negative illness appraisals (controllability, timeline and emotional consequences).
- 3) Insecure attachment style will also be associated with these key caregiving variables (distress, negative care-giving appraisals, negative illness appraisals).
- 4) The relationship between attachment and caregiving variables will be mediated by levels of EE.

## **Method**

### **Participants**

Participants were the identified caregivers of service users from three Early Intervention for Psychosis Services (EIS) within West London Mental Health NHS Trust. The services accept people aged 14 - 35 years who have experienced a first-episode of psychosis. All service users have a diagnosis of psychosis confirmed by a psychiatrist in accordance with ICD-10 criteria (WHO, 1992). Care Coordinators were asked to identify contactable carers who met the following inclusion criteria: (1) individuals who willingly classified themselves as a caregiver; (2) who either lived with the service user or had at least three face-to-face weekly contacts with the service user, totaling at least 10 hours including some telephone calls; (3) had sufficient English language skills to complete the assessment questionnaires; and (4) were over the age of 18 years. Carers of service users who had a primary diagnosis of substance abuse, suffering from any known organic disorder or with a moderate-to-severe learning disability were excluded.

### **Sample Size**

Prior to commencing the study, a power analysis was conducted in order to estimate the sample size. No previous studies were identified that had specifically examined the relationship between expressed emotion and caregiver adult attachment style within early psychosis, therefore research investigating similar constructs was used to determine the sample size for this study. Berry et al., (2008b) looked at the relationship between professional caregivers' attachment style and 'psychological mindedness' (attempts to understand a person's problem) and found that staff who were less 'psychologically minded' were more avoidantly attached ( $N=20$ ,  $r= .55$ ,  $p= .018$ ). This along with other relevant studies in the caregiver literature were considered (e.g. McNab, Haslam & Burnett, 2007;

Paley, et al., 2000) and effect sizes ranged from 0.23 – 0.55. Consequently, sample size was calculated (using GPower3; Faul, Erdfelder, Buchner & Lang, 2009) based on an effect size of 0.4 (using a midpoint between 0.23 - 0.55) with alpha setting at 0.05, power at 0.80, and a two-tailed hypothesis. Results indicated that a sample of 46 would be required.

## **Design**

A cross sectional design was used. Participants completed an interview and a series of self-report measures.

## **Measures**

A battery of questionnaires were administered with each caregiver (see appendix 3 for copies) including:

**Caregiver Information Questionnaire:** This included questions relating to socio-demographic information such as: age, gender, ethnicity, relationship to the service user and how long the person had been a caregiver. In addition, non-identifiable information about the service user was collected, for example age and gender.

**Attachment Style:** The Relationship Questionnaire (RQ: Bartholomew & Horowitz, 1991) is a four-item questionnaire measuring attachment styles in relation to close adult relationships. Respondents are required to read four statements, each reflecting a different attachment style: secure (positive image of self and others), preoccupied-anxious (negative image of self but a positive image of others), dismissing-avoidant (positive image of self and

negative image of others) and fearful-avoidant (negative image of self and others).

Respondents are then asked to indicate how much they agree with each statement on a 7-point Likert scale (from 1= disagree strongly to 7 = agree strongly) and then separately indicate which of the same four statements is most characteristic of their general relationship style. Thus, for each participant the questionnaire yields a score (between 1-7) for each of the four different attachment styles in addition to a categorical 'best fit' style. Whilst both scoring methods can be used, the authors (Bartholomew & Horowitz, 1991), note a move away from categorical classification of attachment in the literature, and recommend the continuous method. The RQ has good psychometric properties (Griffin & Bartholomew, 1994) and is widely used for research purposes.

**Observer-Rated Caregiver Expressed Emotion:** The Five-Minute Speech Sample (FMSS; Magana et al., 1986) is an observer-rated measure of expressed emotion. The FMSS is widely favoured for research purposes, offering a brief alternative to the Camberwell Family Interview (CFI; Leff & Vaughn, 1985), which is considered to be the 'gold standard' measure of EE. The FMSS has good psychometric properties and predictive validity in the course of schizophrenia (Maron, Munitz, Jones, Weizman, & Hermesh, 2005). The FMSS rating is derived from statements made by a service user's relative after they are asked to talk for five minutes about the relationship with the person they care for. The FMSS is audio-recorded and later transcribed and coded for both content and emotional tone. There are a number of subscales (criticism, EOI, dissatisfaction, positive remarks and warmth), which are subsumed under the categories of High and Low EE. Caregivers are assigned a high EE score if they express criticism, indicate EOI or both. Criticism might include caregivers expressing dissatisfaction or resentment towards the service user whereas EOI includes overprotective behaviours or lack of objectivity. 'Borderline' ratings are obtained if carers express attitudes indicative of criticism or over-involvement but do not quite meet full criteria. It has been noted in the literature that the FMSS misses 20-30% of those rated as

high EE by the CFI and it is suggested that coding borderline scores as high EE increases concordance with the CFI (Shimodera et al., 2002). All borderline cases were therefore classified as high EE for this study. All speech samples were transcribed and coded by the author (MC). Fifty percent of the samples were then independently coded by an expert rater (JO) and inter-rater agreement was calculated using Kappa, at 0.7, considered good agreement (Cohen, 1960).

**Self-Reported Caregiver Expressed Emotion:** A self-report measure of EE was obtained using the Family Questionnaire (FQ; Wiedemann, Rayki, Feinstein & Hahlweg, 2002). This is a 20-item self-report questionnaire measuring expressed emotion on two subscales: EOI and Critical Comments (criticism). Criticism includes unfavourable statements about the service user's personality or behaviour and EOI includes statements related to intrusiveness or over-protectiveness towards the service user. Carers are asked how often they have responded to the service user in this way and each item is rated on a 4-point Likert scale (1 = never/rarely to 4 = very often). The FQ rates respondents on a continuous scale yielding a maximum score of 40 for each subcategory. Scores of 23 or above indicate High Criticism and 27 or above indicate High EOI on the respective scales (Wiedemann et al., 2002). The FQ is an efficient alternative to the Camberwell Family Interview and has good correlations with the CFI subcategories as well as with overall high and low EE ratings (Wiedemann et al., 2002). The FQ displays similar levels of accuracy but higher sensitivity compared to the FMSS (Magana et al, 1986). The internal consistency for this sample was calculated using Cronbach's alpha, calculated to be .83 for criticism, and .87 for EOI, both considered good (Cohen, 1960).

**Caregiving Experiences:** The Experience of Care Giving Inventory (ECI; Szmukler

Burgess & Herrman, 1996) is a 66-item measure assessing ten relevant areas of caregiving, which includes eight negative aspects (difficult behaviour, negative symptoms, stigma, problems with services, effects on the family, need for back-up, dependency and loss) and two positive aspects (good and positive experiences). The ECI asks how often carers have thought about each issue over the last month, on a scale of 0 = never to 4 = nearly always. This measure is recognised as the most reliable and valid measure of caregiving experiences and has excellent psychometric properties (Szmukler et al., 1996). It has also been used extensively with caregivers, including first episode psychosis populations (e.g. Tomlinson, Onwumere & Kuipers, 2014; Tennakoon et al., 2000). The internal consistency for this sample was calculated using Cronbach's alpha at 0.9, considered excellent (Cohen, 1960).

**Illness Beliefs:** The Brief-Illness Perception Questionnaire - Carers version (BIPQ-C; Broadbent, Petrie, Main, & Weinman, 2005) is a modified version of the original Illness Perception Questionnaire (IPQ; Weinman, Petrie, Moss-Morris, & Horne 1996). The BIPQ-C is a nine-item measure designed to be a brief assessment of caregivers' cognitive and emotional representations of an illness and has shown good validity across a variety of illnesses. Versions of the IPQ have been adapted and used for psychosis and for carer populations (e.g. Kuipers et al., 2007). The BIPQ-C assesses illness beliefs across a number of domains: identity, consequences, cause, timeline and cure-control. No overall score is calculated, rather individual domains can be used, as required. In line with the hypotheses of this study, only the personal control (how much control the caregiver believes a person has over their illness), timeline (chronicity of illness) and emotional representation (how much the illness affects the caregiver emotionally) scales were analysed.

**Carer Distress:** The Depression Anxiety and Stress Scales (DASS-21; Lovibond &

Lovibond, 1995a) is a screening tool for psychological well-being in the general population. The 21-item questionnaire is a quick, reliable and sensitive measure with good psychometric properties (Lovibond and Lovibond, 1995a; 1995b). Respondents are asked to rate how they feel about a variety of health indicators on a four-point Likert scale. The DASS-21 has three subscales: Depression, Stress and Anxiety and a 'total score', which can be used as an overall indicator of negative affect or psychological distress (Osman et al., 2012). The internal consistency for this sample was considered excellent (Cohen, 1960), with a Cronbach's alpha of .92.

## **Procedure**

The identified carers were approached by the care coordinator to take part in the research via a letter of invitation (see appendix 2). If carers gave verbal consent to be followed up by the researcher, they were contacted, provided with an information sheet (see appendix 2) and had the opportunity to ask questions about the study. Carers were informed that their participation was voluntary, they could withdraw at any time and that this would not influence the level of care they or the service user would receive.

The researcher then arranged to meet each participant face-to-face at home or at the team base at which point written, informed consent was obtained. Questionnaires were completed in the same order for each carer and the researcher was available afterwards to answer any questions the carer may have. The measures took approximately 60 minutes to complete with additional time for discussion and questions if required. Participants were compensated ten pounds for their time.

## **Ethics**

This study was approved by the National Research Ethics Service (NRES) Committee London – Fulham (Research Ethics Committee reference: 14/LO/1252; see appendix 1 for copy of approval letter). Participants were informed that their responses were confidential, unless risk issues were disclosed, in which case the researcher would pass this information on to the clinical team (for example if harm to self or others in relation to either the carer or service user was disclosed during the interview). Participants were made aware that their information would be handled in accordance with the Data Protection Act (1998).

## **Data Analysis**

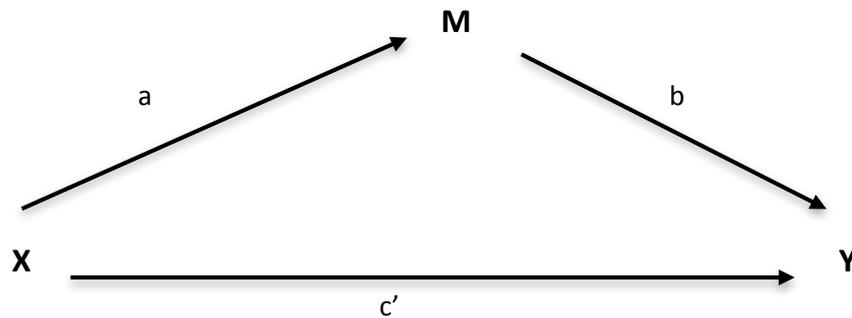
The data were analysed using SPSS version 21 (SPSS Inc, 2013). Two primary variables included 1) the attachment dimensions: Preoccupied-Anxious, Fearful-Avoidant and Dismissive-Avoidant (RQ, Bartholomew & Horowitz, 1991) and 2) expressed emotion, including both dichotomous observer-rated variables (high and low EE: FMSS, Magana et al., 1986), and continuous self-report dimensions (EOI and criticism: FQ, Wiedemann et al., 2002). Secondary variables included: illness appraisals (control, timeline and caregiver emotional representation, BIPQ-C, Broadbent et al., 2005), caregiver distress (DASS-21; Lovibond et al., 1995a) and negative experiences of caregiving (ECI; Szmukler et al., 1996).

Prior to hypothesis testing, normality distributions were assessed using the Shapiro-Wilk test, which is generally suited to smaller sample sizes. Analysis of each attachment style revealed that the data was skewed. Unsuccessful attempts were made to transform skewed data sets using log-transformations. Therefore, all data sets were left untransformed, but both parametric and non-parametric tests (using Mann Whitney *U* and Spearman's rank correlation) were completed for all analyses. As both were significant, only parametric results are reported.

Following protocol from previous studies researching EE (Paley et al., 2000; Bentsen et al, 1998), attempts were made to establish the independence of data in the three families where data was collected from two carers and from one family where one caregiver had provided data about two members of their family. Firstly, levels of EE were examined across these data points and it was established that there was only one family whose carers both contained the same EE profile. The carer who provided responses for two individual family members had different EE profiles for each relative. Secondly, one data point was randomly selected from each family group and all analyses were repeated excluding these data. As this did not change the main findings, it was decided that all 40 relationship sets could be examined as independent data sets and only the main analyses is reported in the text (see appendix 4 for details of analyses excluding family members).

The analyses included multiple testing and a relatively small sample size. As such, specific *p*-values and effect sizes (or confidence intervals where appropriate) are provided along with an explicit note to treat with caution *p*-values that are near the significance level of 0.05. It is also recommended that the findings are replicated with a larger sample.

The relationship between the dichotomous observer-rated EE variables, attachment and caregiving variables were evaluated using independent group t-tests. Pearson's correlational analyses were employed to explore the associations between continuous EE dimensions, attachment and the caregiving variables. Following this, a series of mediation analyses were used to test whether the relationship between attachment style and caregiving variables were mediated by expressed emotion. Mediation analysis tests the effect of the relationship between the causal variable (X) and the outcome variable (Y) through a third variable (M) known as a mediator (see figure 1). The relationship between variables X and Y in mediation (*c'*) is the *direct* effect. If X no longer affects Y once the mediating variable (M) is controlled for, complete mediation is considered to have occurred. Partial mediation occurs when the strength of the relationship between X and Y is reduced by the mediator, but not to zero.



**Figure 1.** Mediation relationships

A widely used method of testing mediation is that proposed by Baron and Kenny (1986), however this method has been criticised for not directly testing the indirect effect, rather it is inferred via a process of deduction after running a series of multiple regression analyses (Preacher & Hayes, 2004). There are now a number of ways to directly test for mediation. We chose to use a PROCESS script developed by Hayes and Preacher (2014) with tests for indirect effects using bootstrapping (based on 1000 bootstrapped samples).

## Results

### Descriptive Information

A total of 61 carers provided verbal consent to being approached by the researcher. Following this, 39 carers (64%) agreed to take part in the study. Reasons for not taking part included: carers being non-contactable or not available following initial contact (n=12), too busy (n=6), not interested following further information (n=2) and too distressed to talk about experiences (n=2). The 39 individual carers who participated in this study, yielded 40 caregiving relationship sets. One of the respondents was a caregiver for two members of

their family with early psychosis (two sons), and therefore provided separate responses for these two individual service users. For three service users, responses were provided from two caregivers (for example a mother and father). Thus for the 40 care-giving response sets, there were 39 individual carers who related to 37 individual service users.

**Caregiver Demographics.** As shown in Table 1, the majority of caregivers were mothers in their early 50s who lived with the service user. Approximately half the sample was married or co-habiting, and just under half were in full or part-time employment. Carers were asked to describe their ethnicity and responses were grouped into the following broad categories: Caucasian, Asian, Black and ‘Other’. For the purposes of analysis these categories were further reduced to Caucasian (n=18, 46%) and non-Caucasian (n=21, 54%).

**Service User Demographics.** The majority of service users were male (78%, n=29) with a mean age of 24.68 years (SD = 4.55). At the time their family member took part in the study, 8% (n=3) were an inpatient. The average length of time service users had been under the care of the EIS was 16.6 months (SD = 13.79).

**Caregiving Variables.** Mean scores for the caregiving variables are shown in Table 2. Analyses were conducted only to test *a priori* hypotheses to minimise the risk of Type II errors. However, the means and standard deviations for all the caregiving variables subscales are reported here to characterise the sample.

Table 1  
*Participant demographics and characteristics*

Demographic information	N=39*
Gender (female) (%)	28 (72)
Age, mean (SD) [Range, in years]	50.95 (11.04) [20-72]
Ethnicity	
Caucasian (%)	18 (46)
Asian (Indian or Pakistani)	12 (31)
Black	6 (15)
Other	3 (8)
Married or Cohabiting (%)	21 (54)
Employed (full or part-time) (%)	19 (49)
Duration of self-reported caregiving in months, (N=40): mean (SD) [Range, in months]	29.65 (20.51) [4 – 96]
Length of time under the care of the EIS, months (N=26 <sup>a</sup> ): mean (SD) [Range in months]	16.58 (13.79) [1-51]
Relationship to service user (N=40) (%)	
Parent	34 (85)
Spouse / partner	1 (2.5)
Sibling	4 (10)
Aunt	1 (2.5)
Living with service user (N=40) (%)	30 (75)
Carers with a close friend or confidante, N (%)	33 (85)

*Note.* N=39 unless otherwise specified. <sup>a</sup>Missing data as care coordinators did not have access to this information for all service users

This sample was found to be comparable with others in the caregiving literature on early psychosis, with similar levels of reported negative caregiving experiences (e.g. Onwumere et al., 2008; Tomlinson et al., 2014 & Jansen et al., 2014a). Of note, nearly half the sample (45%) met the criteria for at least one of the following: mild depression, anxiety

or stress. This finding is again consistent with the literature where levels of distress are generally high in caregivers of people with psychosis (30% meeting clinical criteria for depression or anxiety in Onwumere et al., 2015).

Table 2  
*Mean, standard deviation and ranges of caregiving variables*

Caregiving Variable	Mean	SD	Range
Caregiving Experiences (ECI) (n=40)			
Negative (range 0-208)	91.25	37.82	10-154
Positive (range 0-56)	34.00	9.23	17-53
Distress (DASS-21) (n=39)			
Stress (range 0-21)	8.05	5.61	0-19
Anxiety (range 0-21)	4.10	4.20	0-15
Depression (range 0-21)	5.62	5.04	0-18
Total Score (range 0-63)	17.82	12.48	0-42
Caregiving Appraisals (BIPQ, range 0-10) (n=40)			
Consequences	7.68	2.43	2-10
Timeline	5.80	2.65	0-10
Personal control	4.35	2.80	0-10
Treatment control	7.20	2.52	2-10
Identity (symptoms)	5.78	2.82	0-10
Concern	8.20	2.40	2-10
Coherence	7.63	2.34	0-10
Emotional Representation	7.55	2.50	0-10

*Note.* BIPQ = Brief Illness Perception Questionnaire; DASS-21 = Depression, Anxiety Stress Scales, 21-item version; ECI = Experience of Caregiving Inventory.

**Attachment.** Table 3 provides the means and standard deviations for each attachment style. When asked to identify an attachment style that best described their

relationships, 41% (n=16) of carers reported Secure, 33% (n=13) endorsed dismissing-avoidant, 18% (n=7) reported fearful-avoidant, and 8% (n=3) identified preoccupied-anxious as most representative. Thus in total, 59% of respondents fell into the combined insecure attachment categories. This is slightly different to general population samples (Western), where approximately 40% are reported to have insecure styles (Mickelson, Kessler & Shaver, 1997). In line with the dimensional approach to attachment and as recommended by Bartholomew and Horowitz (1991), the continuous rating scales were used to test hypotheses. Furthermore, consistent with the original hypotheses, only the insecure attachment styles were used for the purpose of analysis (however secure is included here to characterise the sample).

Table 3  
*Attachment style descriptive statistics*

Attachment Style (range 1-7)	Mean	SD	Range
Secure	4.92	1.84	1-7
Preoccupied-Anxious	2.92	1.75	1-7
Fearful-Avoidant	3.49	2.13	1-7
Dismissing-Avoidant	3.95	1.97	1-7

*Note.* Attachment style measured by the Relationship Questionnaire (RQ; Bartholomew et al., 1994).

N=39

### **Expressed Emotion.**

***Observer-Rated Expressed Emotion (FMSS).*** Approximately half of the caregiving relationships were observer-rated as High EE (n=19, 45%) using the ‘Borderline-

High EE criteria' as detailed in the method (Shimodera et al., 2002). Overall, ten participants were rated high EE using the strict criteria and a further nine rated borderline-high EE. We hereafter referred to all borderline and high EE participants in the remainder of the thesis as 'high EE' for simplicity. The remainder of the sample (n=21, 55%) were classified at low EE. This proportion is in line with the literature in this field (Jarbin, Grawe & Hansson, 1999).

***Self-Report Rating of EE (FQ).*** Mean criticism score was 22.73 (SD=5.93) and mean EOI was 28.83 (SD=6.34). Using Wiedemann et al., (2002)'s cut-off for high criticism as 23 or above and a cut-off for high EOI as 27 or above, 55% (n=22) of the sample fell into the high criticism category and 57.5% (n=23) of the sample high EOI. Mean results for criticism and EOI in this sample are in line with the literature (Wiedemann et al., 2002).

***Convergence Between Observer-Rated and Self-Report EE Measures.*** In order to assess the agreement between the observer-rated and self-report EE measures, independent samples *t*-tests were performed comparing levels of self-report EOI and criticism across the observer-rated high and low EE groups. Table 4 shows mean scores on the self-report measure of EOI and criticism (assessed by the FQ) in relation to the observer-rated EE measure (assessed by the FMSS). Carers who were observer-rated as displaying high EE reported significantly higher self-report EOI and criticism than carers rated as low EE, suggesting both measures are assessing similar constructs.

Table 4  
*Convergence between observer-rated and self-report EE measures*

Self-report EE (FQ)	Observer-rated EE (FMSS)		<i>t</i> -test	<i>p</i>
	High (n=19)	Low (n=20)		
Criticism, M ( <i>SD</i> )	25.58 (4.86)	20.14 (5.71)	3.23	.003*
EOI, M ( <i>SD</i> )	31.84 (4.68)	26.10 (6.50)	3.18	.003*

*Note.* Self-report EE rated by FQ (Wiedemann et al., 2002) were compared to high and low EE categories as rated by the FMSS (Magana et al., 1986) using independent *t*-tests.

### Assessing Demographic and Clinical Confounds

Preliminary analyses were carried out to determine whether there were any associations between the demographic variables and the main variables of interest (attachment, EE and caregiving variables). This was conducted in order to determine whether important characteristics such as duration of caregiving impacted variables such as levels of distress or negative caregiving experiences. Dismissing attachment style was associated with a longer duration of self-reported caregiving ( $r(40) = .36, p = 0.047$ ). There were no other significant associations (see appendix 4 for full analyses of demographic variables).

### Hypotheses Testing

**Hypothesis One: Insecure Attachment and High Expressed Emotion.** In line with the main hypothesis, Fearful-Avoidant attachment was significantly positively correlated with self-report high EOI ( $r(40) = .362, p = .022$ ). However, as it can be seen in Tables 5 and 6, contrary to predictions, there were no other significant associations or group differences between attachment style and observer-rated expressed emotion.

Table 5  
*Relationship between attachment style and self-report EE*

Attachment Style	Self-Report EE					
	Criticism			EOI		
	<i>r</i>	<i>p</i>	CI	<i>r</i>	<i>p</i>	CI
Preoccupied-Anxious	.034	.837	-.288 - .343	.228	.157	-.104 - .499
Fearful-Avoidant	.254	.113	-.021 - .498	<b>.362</b>	<b>.022*</b>	<b>.054 - .605</b>
Dismissing-Avoidant	.225	.162	-.076 - .504	.163	.314	-.170 - .485

\* Correlation is significant at the .05 level (2-tailed for Pearson's *r*).

Table 6  
*Relationship between attachment style and observer-rated EE*

Attachment Style	Observer-rated EE				
	High EE, Mean (SD)	Low EE, Mean (SD)	<i>t</i>	<i>p</i>	Effect Size ( <i>r</i> )
Preoccupied-Anxious	3.21 (1.72)	2.67 (1.78)	1.15	.256	0.18
Fearful-Avoidant	3.74 (1.97)	3.14 (2.29)	.88	.387	0.14
Dismissing-Avoidant	4.47(1.87)	3.48 (1.94)	1.65	.107	0.25

*r* effects: small  $\geq .10$ , medium  $\geq .30$ , large  $\geq .50$ ;

**Hypothesis Two: Caregiving Variables Associations with EE.** Tables 7 and 8 display the associations between caregiving experiences and EE.

***Experience of Caregiving (ECI).*** Negative caregiving experiences were associated with subjective high Criticism ( $r(40) = .52, p < .0001$ ) and subjective high EOI ( $r(40) = .64, p < .0001$ ). There were no significant differences in caregiving experiences using the observer-rated EE measure ( $p = 0.055$ ).

***Distress:*** Increased caregiver distress was associated with high self-reported criticism ( $r(39) = .52, p < .001$ ) and EOI ( $r(39) = .63, p < .001$ ). This finding was supported by the observer-rated EE rating; those rated as high EE reported increased distress ( $t(37) = .31, p = .003$ ).

***Illness Appraisals:*** (a) Timeline: Carer belief that the illness would last a long time was associated with higher levels of criticism ( $r(40) = .43, p = .006$ ). There was no association for EOI. (b) Controllability: lower levels of self-reported EOI were significantly associated with believing that the service user had more personal control over their illness ( $r(40) = -.45, p = .002$ ). There was no significant association between controllability and criticism. (c) Emotional Representation (self-reported emotional impact of the illness of caregiver): greater emotional impact was associated with self-reported criticism ( $r(40) = .31, p < .001$ ) and self-reported EOI ( $r(40) = .72, p = .026$ ). However this finding was not replicated by the observer-rated measure of EE ( $p > .05$ ).

**Table 7**  
*Associations between self-reported expressed emotion and caregiving variables*

Caregiving Variables	Self-Report EE					
	Criticism			EOI		
	<i>r</i>	<i>p</i>	CI	<i>r</i>	<i>p</i>	CI
Negative Caregiving Experiences (ECI) (n=40)	<b>.52</b>	<b>&lt;.001**</b>	<b>.236 - .746</b>	<b>.64</b>	<b>&lt;.001**</b>	<b>.444 - .808</b>
Distress (DASS-21) (n=39)	<b>.63</b>	<b>&lt;.001**</b>	<b>.371 - .824</b>	<b>.52</b>	<b>&lt;.001**</b>	<b>.281 - .719</b>
Caregiving Appraisals (b-IPQC) (n=40)						
Timeline	<b>.43</b>	<b>.006**</b>	<b>.196 - .650</b>	.577		-.186 - .356
Personal control	-.26	.053	-.593 - .059	<b>-.45</b>	<b>.002**</b>	<b>-.651 - -.258</b>
Emotional Representation	.31	0.26*	-.039 - .565	<b>.72</b>	<b>&lt;.001**</b>	<b>.561 - .822</b>

*Notes.* Significant at \**p*=0.05, \*\**p*=0.01 (2-tailed for Pearson's *r*). b-IPQC= brief-Illness perception Questionnaire; DASS-21 = Distress, Anxiety Stress Scales; ECI= Experience of Caregiving Inventory

**Table 8**  
*Associations between observer-rated expressed emotion and caregiving variables*

Caregiving Variables	Observer-rated EE				
	High EE, Mean (SD)	Low EE, Mean (SD)	<i>t</i>	<i>P</i>	<i>Effect size (r)</i>
Negative Caregiving Experiences (ECI) (n=40)	103.2 (29.44)	80.38 (41.82)	1.93	.055	.30
Distress (DASS-21) (n=39)	15.75 (7.54)	8.1 (7.65)	<b>3.12</b>	<b>.003**</b>	<b>.46</b>
Caregiving Appraisals (b-IPQC) (n=40)					
Timeline	6.32 (2.45)	5.33 (2.78)	1.76	.247	.27
Personal control	4.16 (2.61)	4.52 (3.01)	-.409	.685	.07
Emotional Representation	8.26 (1.82)	6.90 (2.86)	1.77	.85	.28

*Notes.* Significant at \**p*=0.05, \*\**p*=0.01; *r* effects: small  $\geq .10$ , medium  $\geq .30$ , large  $\geq .50$ ; b-IPQC= brief-Illness perception Questionnaire; DASS-21 = Distress, Anxiety Stress Scales; ECI= Experience of Caregiving Inventory.

### **Hypthosis Three: Caregiving Variables Associations with Insecure Attachment**

**Style.** Table 9 displays the associations between caregiving variables and attachment.

Fearful-avoidant attachment style was significantly correlated with levels of caregiver distress ( $r(39) = .43, p=.006$ ) and higher emotional impact of the illness on the caregiver ( $r(40) = .37, p=.019$ ), the latter also being associated with insecure-preoccupied attachment style ( $r(40) = .32, p=.044$ ). There were no other significant associations between attachment style and caregiving variables.

Table 9  
*Associations between attachment style and caregiving variables*

Caregiving Variables	Attachment Style								
	Preoccupied-Anxious			Fearful-Avoidant			Dismissing-Avoidant		
	<i>r</i>	CI	<i>p</i>	<i>r</i>	CI	<i>p</i>	<i>r</i>	CI	<i>p</i>
Negative Caregiving Experiences (ECI) (n=40)	.26	-.103 - .524	.113	.22	-.108 - .460	.172	.11	-.233 - .421	.514
Distress (DASS-21) (n=39)	.26	-.052 - .551	.115	<b>.43</b>	<b>.181 - .675</b>	<b>.006**</b>	.06	-.251 - .359	.728
Caregiving Appraisals (B-IPQC) (n=40)									
Timeline	.12	-.241 - .341	.48	.19	-.143 - .433	.235	-.285	-.538 - -.032	.075
Personal control	-.16	-.407 - .216	.347	-.21	-.433 - .095	.184	-.07	-.330 - .204	.659
Emotional Representation	<b>.32</b>	<b>.033 - .550</b>	<b>.044*</b>	<b>.37</b>	<b>.127 - .557</b>	<b>.019*</b>	.15	-.112 - .422	.360

Significant at \**p*=0.05, \*\**p*=0.01 (2-tailed for Pearson's *r*)

Notes. ECI= Experience of Caregiving Inventory; DASS-21 = Distress, Anxiety Stress Scales; BIPQC= brief-Illness perception Questionnaire. Attachment measured by FQ.

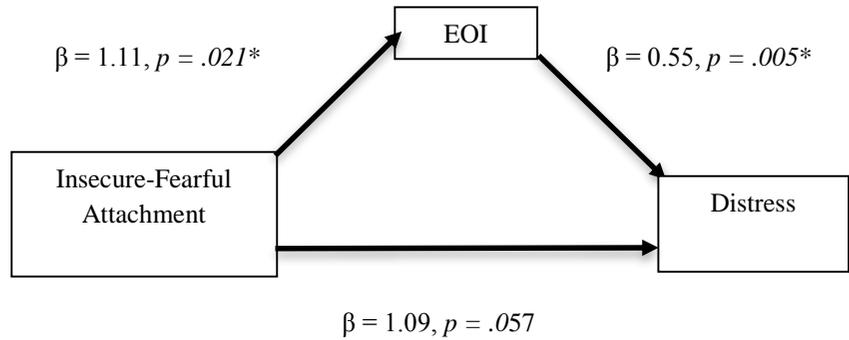
#### **Hypothesis Four: EE as Mediator of the Influence of Attachment on**

**Caregiving.** From the original hypotheses, there were two sets of variables that could be tested using mediation analyses: firstly, the potential mediator of self-reported EOI was significantly associated with both the IV ‘fearful-avoidant attachment’ and the DV ‘distress’. Secondly, the potential mediator EOI was significantly associated with ‘fearful-avoidant’ attachment and negative emotional representation appraisals.

**Distress.** As displayed in Figure 2, the relationship between fearful-avoidant attachment and distress was partially mediated by EOI. There was a significant indirect effect of fearful-avoidant attachment on overall distress through emotional over-involvement behaviour,  $ab = 0.15$ , BCa CI (0.42-0.38). The mediator could account for approximately 12% of the total effect,  $Rsq = 0.12$ .

**Emotional Representation.** The relationship between fearful-avoidant attachment and emotional representation (how much the caregiver is impacted emotionally due to the illness) was partially mediated by EOI. There was a significant indirect effect of fearful-avoidant attachment on overall emotional representation through emotional over-involvement behaviour,  $ab = 0.24$ , BCa CI (0.03=4-0.45). The mediator could account for approximately 12% of the total effect,  $Rsq = 0.12$ .

Model 1: Insecure attachment and distress

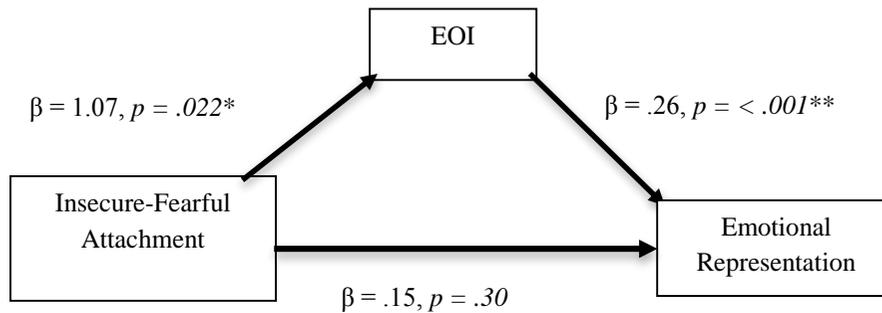


Total Effect:  $\beta = 1.71, p = .006^*$

95% CI = .51 - 2.90

Indirect Effect:  $\beta = .61, 95\% \text{ CI} = .15 - 1.55$

Model 2: Insecure attachment emotional representation (emotional impact of illness on caregiver)



Total Effect:  $\beta = .43, p = .019^*$

95% CI = .08 - .79

Indirect Effect:  $\beta = .28, 95\% \text{ CI} = .05 - .59$

**Figure 2.** Illustration of the mediation effect on distress and emotional representation. Insecure-Fearful attachment affects the outcomes indirectly through EOI behaviours. Distress, measured by DASS-21; Emotional Representation measured by bIPQ, Attachment measure by RQ, EOI measured by FQ.

## Discussion

To the author's knowledge, this is the first investigation to examine the relationship between caregiver insecure attachment, levels of expressed emotion and related caregiving variables in early psychosis caregivers. The number of statistical tests was high, and as such the results should be treated with caution and replication of the findings is required. However, all analyses were based on *a priori* hypotheses, and there were a number of associations that were higher than anticipated given the small sample size.

### Expressed Emotion and Caregiving Variables

As predicted by our hypotheses, and in line with the previous literature in this field (e.g. Barrowclough & Hooley, 2003; Raune, 2004; Kuipers et al., 2006), carers who reported higher levels of EOI and criticism also reported experiencing higher levels of distress, negative caregiving experiences (burden) and greater emotional impact of the illness. In addition, carers who believed their relative had little control over symptoms, reported that they engaged in higher levels of emotionally over-involved caregiving behaviours. Carers who believed that the illness would have a longer duration, reported higher levels of criticism towards their relative.

Previous findings have suggested that carers who believe the individual has more control over symptoms and illness tend to be more critical (Barrowclough et al., 1997). However, contrary to predictions, no associations between criticism and controllability were found in this study. It is possible that within an early psychosis sample the link between criticism and control is less stable but becomes more so over time (where this finding is generally quite robust, Barrowclough & Hooley, 2003; Brewin, MacCarthy, Duda & Vaughn 1991). Onwumere et al., (2008) noted differential levels of perceived control in caregivers of

early psychosis depending on the duration of illness. Further studies have also reported that criticism is not stable over time (Kavanagh, 1992; Lenoir et al., 2002).

Analyses of the observer-rated and self-report measures of EE used in this study indicated that they were significantly related to each other. However, differences in the associations between each of these measures and the caregiving variables were revealed. Higher levels of distress were found in those observer-rated as displaying high EE, but no further group differences on the caregiving variables were found. The two measures of EE used in this study vary in important ways. The FMSS (Magana et al., 1986) provides an observer-rated, categorical 'high EE' classification, combining both EOI and criticism scales. In contrast, the FQ (Wiedemann, et al., 2002) provides self-reported dimensional measure of EOI and criticism separately. Differences have been noted on self-report measures of EE, where self-reported high EE was found to be more closely associated with burden in comparison to other studies (King et al., 2003). Furthermore, the differences in associations across the two measures found in this study lends support to the notion that EE is not a unitary construct, and may be better understood when constituent parts are studied separately (Alvarez-Jimenez et al., 2010). This may be particularly relevant for the early psychosis groups when caregiving responses are emerging, changing and less stable. Detailed understanding the individual components of EE may allow for interventions at this early stage of the illness to be more tailored in order to prevent the entrenchment of unhelpful caregiving responses.

### **Is Attachment Style Associated with Expressed Emotion and Caregiving Variables?**

Fearful-avoidant attachment style was associated with higher levels of self-reported emotional over-involvement. However, contrary to predictions, no associations were found between attachment style and criticism or observer-rated expressed emotion. Attachment

style was not found to be associated with illness beliefs or negative caregiving experiences (burden), however, a relationship was observed between higher fearful-avoidant attachment and two caregiving responses: increased caregiver distress and increased perceived emotional consequences of the illness on the caregiver. Furthermore, the key finding in this study was that emotional over-involvement was found to partially mediate the influence of fearful-avoidant attachment on both distress and appraisals about the adverse emotional impact of illness, thus supporting the mediation hypothesis for these two caregiving variables.

The results from this study suggest a complex relationship between adult attachment and EE. There may be some conceptual overlap between attachment and EE for example each label may be describing similar behaviours; indeed Patterson (2005) explores the links between attachment and EE highlighting that EE components (specifically EOI and criticism) might be understood as particular types of attachment behaviours. Bowlby (1980) suggested that criticism may be an adaptive response to any perceived loss; designed to re-establish what has been lost. Similarly, Birchwood (1992) proposed that criticism seen in families of individuals with schizophrenia may be a coping strategy to deal with the perception of loss (such as loss of social status). However, results from this study indicate that whilst there may be a relationship between the two constructs, they are separate entities, each having a differential impact on caregiving variables.

### **Attachment and Caregiving in Early Psychosis**

This study suggested that a portion of the variance in distress experienced by caregivers may be accounted for by levels of fearful-avoidant attachment style and mediated by the amount of emotionally over-involved behaviours carers engage in. The working models of 'self and other' that are thought to underlie each attachment style have a central role in guiding the way an individual responds to stressful experiences, including their emotion regulation and personal well-being (Carnelley, Pietromonaco & Jaffe, 1994; Cooper,

Shaver & Collins, 1998; Mikulincer & Florian, 1998). A fearful-avoidant attachment style is characterised by a negative self-image combined with a fear that others cannot be trusted to be loving and available (Bartholomew & Horowitz, 1991). Those who strongly identify with this attachment style are more likely to have experienced abuse or neglect in their own early caregiving environments (Brennan, Shaver & Tobey, 1991; Shaver & Clark, 1994). It is understood to be a mixed and somewhat confused attachment style, where the individual has a desire for close relationships and therefore seeks them out but this is combined with an intense fear of getting hurt so at the same time they experience discomfort with closeness and so avoid it (Mikulincer & Shaver, 2010). It has been noted that under stress, adults who are high on this attachment dimension can display apparently contradictory behaviour for example they may engage in both approach and avoidance strategies (Bartholomew & Horowitz, 1991; Cassidy & Shaver, 1999).

Within the general caregiving literature (for example studies looking at romantic relationships), research has generally shown an inverse relationship between fearful attachment and engagement in caregiving behaviours (Carnelley, Pietromonaco & Jaffe, 1996; Feeney & Collins, 2001; Kuncze & Shaver, 1994). It has been understood that a fearful attachment style leads people to mistrust others, and therefore they become less involved in caregiving as a means of self-protection. However, the current study found an association in the opposite direction. Whilst this is contrary to the *general* caregiving literature as described above, this study supports findings in caregiving amongst parents of children with mental illness, where fearful attachment in parents was associated with increased somatic and depressive symptoms – a relationship which was partially mediated by more over-involved and egocentric caregiving behaviours (Farinelli & Guerrero, 2011).

In general relationship contexts, those with more fearful-avoidant attachment styles may provide less caregiving or avoid becoming too involved due to a fear of getting hurt. However, in a context where their own children are affected by mental illness, caregivers may feel compelled and obliged to continue to provide support in spite of their fears (Farinelli &

Guerrero, 2011). Those parents who hold a low or negative view of themselves (consistent with fearful-attachment style) may feel more responsible for their child's difficulties (Farinelli & Guerrero, 2011). Caregiving in early psychosis has been associated with feelings of loss (Patterson et al., 2005), guilt and self-blame (Bentson et al., 1998), and this is related to high emotional over-involvement. Carers may engage in over-compensatory and over-involved behaviours out of guilt and self-blame. Furthermore, providing care in an over-involved manner increases distress and sense of burden (Breitborde, Lopez, Chang, Kopelowick & Zarate, 2009; Jansen et al., 2014a), supporting the findings that attachment and distress is mediated by levels of emotionally over-involved behaviours.

Additionally, people with avoidant or fearful attachment styles generally have difficulty acknowledging negative emotions (Kobak & Sceery, 1988). In the bereavement literature, avoidant attachment patterns have been associated with greater somatic symptoms, and difficulties expressing grief, suggesting that these individuals may defensively (unconsciously) 'block' their distress and engage in more active or distracting strategies (Parkes, 2003). It may be that engaging in overly-involved (more active 'doing' caregiving behaviours), allows individuals to avoid the experiential processing of emotions, which leads to greater distress.

### **The Cognitive Model of Caregiving**

The cognitive model of caregiving (Kuipers et al., 2010) suggests factors related to the relationship between an individual and their family member prior to an episode of psychosis determines caregiving responses (positive, critical or over-involved) and burden of care. Our findings indicate that caregiver attachment style may be an important factor in understanding the quality of the relationship and subsequent caregiving responses, thus contributing to this model of understanding. It should be noted that caregiver attachment was

not associated with criticism, or caregiving variables such as burden, suggesting that there are many aspects of the caregiving process that may be unrelated to caregiver attachment style. Caregiving is a highly complex process where cognitive, emotional, social, biological and environmental factors for both the caregiver and service user are intertwined with the characteristics of the illness itself (Bronfenbrenner, 2009; Kuipers et al., 2010). Thus several inter-related factors will likely contribute to each caregiving appraisal and response.

### **Strengths and Limitations**

An important limitation of this study was the reduced power to examine associations between multiple attachment styles and caregiving variables of interest, as we were unable to recruit the required number of participants (according to the original power calculation). A larger sample would have increased the power and allowed for the examination of the caregiving variables of interest, whilst controlling for multiple independent variables and covariates (such as length of caregiving or symptom severity, and ethnicity). These could also be examined across different types of relationships (for example, examining parental and romantic caregiving relationships separately). A further possibility is that non-significant findings regarding some of the insecure attachment styles, particularly those looking at group differences, arose due to the reduced level of power, thus increasing the possibility of a Type II error. However, despite such limitations, the current study did find significant associations in the predicted direction of the stated hypotheses. Furthermore, this is the first study examining associations between caregiver attachment and EE in early psychosis and whilst the findings should be treated with caution, we do provide preliminary evidence for the hypothesised relationship, thus extending the current understanding of EE and caregiving relationships.

**Design.** The design employed for this study was cross-sectional, and primarily relied on correlational analysis, thus limiting inferences about causation. Caregiving responses are also likely to be circular in their effects across time, for example high levels of distress may impact caregiving experiences and behaviours, which in turn further increase levels of distress. Cross-sectional data does not allow for a clear understanding of the caregiving process over time; some variables may shift, for example people may be more or less critical at different points. An additional limitation of the design pertains to the order of questionnaires; the Five Minute Speech Sample was the first measure presented to participants and by talking openly about their relative, this measure may evoke specific thoughts and feelings that could have had an impact on subsequent responses. Furthermore, the questionnaires were provided to each participant in the same order, which means the study is prone to general order effects such as participant fatigue.

**Sampling.** The sampling method could have resulted in recruiting participants who were not representative of all carers in Early Intervention Service or of people with psychosis more generally. There was a reliance on care-coordinators to initiate the invitation to research, and as such it is possible they invited those carers who were already engaged in the service, or those with whom they had a previously good relationship. There is a further likelihood of bias due to the number of people who did not take part following initial invitation ( $N = 22$ , 36% of those invited). The reason for this was primarily because carers were non-contactable following the initial contact and because carers were too busy or too distressed. Although participation rates in this study were comparable to other peer-reviewed studies recruiting carers (for example Jansen et al., 2014a), no further information was available for those who did not take part. The study may have attracted those caregivers who were highly motivated to take part in research or who were particularly interested in

understanding their family relationships. Difficulties with service engagement and therapeutic relationships have been noted in relation to service users (Tait, Birchwood, & Trower, 2004; Daniel, 2006), and it is possible that carers with highly insecure or avoidant attachment styles may be less likely to engage with services or contribute to research. Additionally, although the study set out to examine all caregiving relationships, it was mainly female parental caregivers who participated. This is common in early psychosis literature, a time when young people are often still living at home (Scazufca & Kuipers, 1997; NICE, 2014), but means the findings cannot be generalised to other types of caregiving relationships such as siblings, romantic partners and so forth.

A final issue with regard to potential confounds in the sample, relates to the inclusion of two carers from the same family and also one carer who reported on two members of family with psychosis. This study aimed to examine all caregiving relationships to understand the relationship between attachment and EE in caregivers, not each service user, which is why the decision was taken to include all carers who wished to take part. However, there are limitations with using this approach (as opposed to one carer for one service user), chiefly, analysing the data from members of the same family as if they were independent samples rather than potentially correlated, represents a methodological issue. Although, equally it can be argued that assuming family members are correlated also presents a similar dilemma. However, all results were re-analysed after randomly excluding one carer from those families who provided more than one data set, and this did not change the significant findings.

**Measurement bias.** The present study predominantly relied upon self-report measures, which raises a number of important issues. Self-report instruments are known to be less reliable both in general and specifically with regard to measuring adult attachment. It has been suggested that narrative interview measures, such as the Adult Attachment Interview (AAI; George, Kaplan & Main, 1985), are the most accurate way to capture attachment

patterns, however this measure takes several hours to administer and score and as such was not feasible for use in this study. Furthermore, the self-report attachment measure used is considered reliable and valid (Ravitz, Maunder, Hunter, Sthankiya & Lancee 2010) and frequently used in research settings allowing for comparison across studies.

A further issue related to attachment measurement surrounds the attachment relationship under examination. This study was interested in how general attachment scripts might become activated and inform caregiving processes. This study therefore measured caregivers' *general* adult attachment style with regard to 'close relationships'. Although individuals have a general attachment style, attachments to specific individuals can vary (Ross & Spinner, 2001) and it would be important for future research to examine caregivers' *specific* attachment to the individual they are providing care for, which may differentially influence levels of EE and other caregiving responses. It is also important to recognise that the process of caregiving is reciprocal; the attachment strategies of the individual may elicit certain responses from caregivers (Dozier Stevenson, Lee, & Velligan., 1991). Insecure attachment is associated with greater psychopathology and psychotic phenomenology (Berry, Roberts, Danquah & Davies, 2014; Korver-Neiber, Berry, Meijer & Haan, 2013) and higher emotional over-involvement in relatives (Dozier et al., 1991). Future research may benefit from a multi-method approach for example, using a combination of observer-rated and self-report attachment measures, in addition to measuring specific attachment relationships and the service users' own attachment style.

Finally, much of the EE literature views families within a negative framework, using terms such as 'critical', 'hostile', and 'over-involved'. Caregivers' valuable contribution in the recovery of those with psychosis is often under-recognised (Kulhara, Kate, Grover & Nehra, 2012). Families frequently show positive regard and warmth toward the service user, and instruments measuring EE do capture these elements. However, the associations that most robustly predict service user outcomes are based on the negative features. Consequently, positive aspects are often neglected as part of routine clinical EE assessment

and in research. It is important to note that warmth and other positive aspects may interact with the critical comments and serve as a protective function (Bhugra & McKenzie, 2003; Kulhara et al., 2012; Bebbington & Kuipers, 1994; Lee, Barrowclough & Lobban, 2014). Research on the more positive aspects of caregiving is small but growing (Cohen Colantoni & Vernich, 2002; Kramer, 1997; Kulhara, et al., 2012) and it would be important for future studies to continue to contribute to this.

### **Clinical Implications and Future Research**

This study contributes to the cognitive model of caregiving for psychosis (Kuipers et al., 2010) and indicates that caregiver attachment styles may be an important factor in understanding caregiving responses. The preliminary findings indicate further research is now required with larger samples and assessing both specific and general attachment styles. Attachment is a lifespan theory (Bowlby, 1980) and thus the relationship between attachment and caregiving variables (specifically EE) would benefit from longitudinal research to analyse a causative role for attachment style and caregiving responses.

There is recognition that attachment theory may help inform the delivery of mental health services (Bucci, Roberts, Danquah, & Berry, 2015), for example those with avoidant attachment may require more flexible approaches to engagement (in line with their ‘approach/avoid’ tendencies). Varying therapeutic approaches in accordance with caregiver attachment styles, may improve services and maximise engagement for families. There is extensive work on attachment-based interventions for those recovering from psychosis, which could also inform caregiver interventions (Gumley, 2006; Tyrell, Dozier, Teague & Falot 1999). Furthermore, if staff endeavour to form trusting relationships despite any initial hostility or avoidance from carers, this may help individuals with generally negative views of others (characterised by avoidant attachment styles), to build confidence in staff and services and increase engagement (Bartholomew 2001; Berry et al., 2008b).

Current evidence-based family interventions in psychosis generally focus on increasing knowledge about the illness, stress management, coping skills training and minimising the risk of relapse (Onwumere, Bebbington & Kuipers, 2011). The findings of this study suggest that caregiver attachment style and caregiving ‘scripts’ may have an important role in the caregiving process. Understanding the influence of caregiver attachment styles may be helpful in reducing both levels of distress in carers and EOI responses towards service users. Clinical interventions should pay attention to caregivers’ own experience of being cared for and aim to better understand carers’ assumptions, expectations and fears around providing care and support for their relatives, particularly in the context of an illness process that is often confusing and unclear. The findings from this study suggest that it may be beneficial to assess for those with high fearful-avoidant attachment styles, particularly when providing interventions that aim to reduce levels of EOI, as this may be contributing to and exacerbating such behaviours. Within family interventions, a clinical focus emphasising the adaptive nature of insecure attachment styles might help avoid stigma or any sense of self blame and guilt which commonly underpin EOI behaviours (Bentsen et al., 1998; Berry, 2008a). Highlighting the role of insecure attachment responses in maintaining unhelpful patterns of caregiving alongside offering alternative and more adaptive strategies would be important for caregivers and consistent with recent NICE (2014) guidance for psychosis and schizophrenia which emphasise the importance of carer based interventions.

Additionally, replicating the wider literature (Barrowclough et al., 2001; Lobban et al., 2005) our findings have provided evidence that beliefs about chronicity (length of time the carer believes the illness may last for) are significantly associated with criticism. These findings suggest that psychoeducation regarding the symptoms and cyclical nature of relapse, in addition to challenging beliefs and assumptions about the chronicity, may help caregivers to better understand and more appropriately respond to their relatives.

## **Conclusions**

Notwithstanding the limitations outlined, this research lends support to the growing body of literature indicating a role for attachment theory in understanding caregiving responses. There is evidence for a relationship between caregiver fearful-avoidant attachment style and distress (including perceived emotional impact of the illness), which is partially mediated by levels of emotionally over-involved behaviours displayed by the caregiver. Attachment theory may offer important contributions to understanding the influences and origins of expressed emotion as well as further understanding caregiver distress. Further research with a larger sample size is now required.

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## **Part Three: Critical Appraisal**

## **Introduction**

This critical appraisal will discuss the process of completing the empirical research, reflecting on the key conceptual and methodological issues encountered while exploring caregiving relationships within early psychosis. I will firstly outline my interest in this area before reflecting on the largely negative focus on caregiving in psychosis found in the literature. Following this, the difficulties of selecting assessment instruments will be considered before discussing issues pertaining to recruitment and selection bias.

### **Personal Context: Impressed by Informal Caregiving**

My interest in this area came from working with individuals experiencing psychosis in a variety of mental health settings including a Crisis-Resolution and Home Treatment Team and an Early Intervention for Psychosis Service. An episode of psychosis does not usually happen in isolation, but will have an impact on family members and those close to the individual (Addington, Coldham, Jones, Ko & Addington, 2003; Addington & Burnett, 2004). Psychosis (particularly the first episode) can be a highly stressful, confusing and uncertain event for a family. It is marked by changes in the behaviour and personality of the person experiencing psychosis as well as changing the dynamic and relationship between family members, particularly for those who take on caregiving roles (Tennakoon et al., 2000).

Reflecting on my previous experiences, I had been struck by the crucial role the family played in supporting an individual with psychosis; it was evident that they coped with considerable challenges and emotional upheaval and many carers described their family members changing beyond recognition during an acute episode. A first episode often occurs in adolescence, a developmentally important time, when young people might be transitioning into work or further education and when families are often preparing for

the person to leave home (Mueser & McGurk, 2004). Following a psychosis, this can all considerably change, and the uncertainty that surrounds prognosis can be very distressing for all involved.

Having facilitated several ‘friends and family’ groups and spoken to a number of different caregivers, I was impressed by the level of support and care they provided in the midst of the difficulties. I witnessed individual and family life being transformed, with family members frequently going to great lengths to provide support in the way they deemed most appropriate. This was often coupled with great personal sacrifice, for example giving up work to care for their relative. The myriad of ways in which carers responded emotionally was evident: hope, anger, frustration, sadness, loss, desperation and despondency all featured, but the underlying impression when working with carers was one of great concern and care for their family member. I became interested in understanding the influences behind caregiving responses and observed that although there were well known associations between high expressed emotion and patient outcomes in the literature (Butzlaff & Hooley, 1998); clinically, little was known about why one carer might display high EE and another not. As I explored the literature further, it became apparent that the evidence base was unclear and further research was required.

### **Positive Aspects of Caregiving**

In notable contrast to my personal encounters, my review of the literature revealed a markedly negative emphasis and language associated with carers, particularly those who might display ‘high EE’ behaviours. Caregiving is often framed as a negative phenomenon and the literature has a tendency to describe families using phraseology such as ‘critical’ and ‘hostile’. The caregivers’ invaluable contributions in the treatment and recovery process is often under-recognised (Kulhara, Kate, Grover

& Nehra, 2012). Families have been found to show positive regard and warmth towards their relative, and caregivers also report positive experiences (Kramer, 1997); however until recently, this has been somewhat neglected in the EE literature (Amerasha & Venkatasubramanian, 2012).

Research on the more positive aspects of caregiving is currently small but growing (Cohen, Colantoni & Vernich, 2002; Kramer, 1997; Kulhara et al., 2012). I was committed throughout this thesis to contribute to a more compassionate and positive understanding of caregiving experiences and responses. I wanted to stay away from the prevalent negative connotations of caregiving in the literature. However, I found this more challenging than anticipated, particularly as the outcomes that are considered most robust, are also those that are negative (for example critical comments: Butzlaff & Hooley, 1998). As such, I was faced with the dilemma of using a qualitative design, exploring hypotheses not grounded in previous research, or building on the evidence-base which has a more negative focus. Given that the investigation of attachment was already a novel and previously unreached topic in caregiving in psychosis, it was decided, with the support of my supervisors, to replicate existing findings in relation to negative caregiving experiences and investigate the role of attachment in such processes. It is important to extend our understanding of the key factors that impact on the caregiving process, including the aspects beyond illness related issues, and I was keen to contribute to a richer understanding of the psychological variables that may play a role in and contribute to the caregiver literature. In writing up this thesis I have tried to offer a balanced understanding of caregivers' experiences and responses without blame or criticism, acknowledging that the caregiving role is indeed very difficult and stressful at times.

## Measurement of Constructs

Deciding upon appropriate measurement instruments is an integral part of the design process for any research. Within this study, significant attention was paid to the measurement of the two main theoretical constructs: attachment and EE. There is extensive discussion in the literature regarding the best way to measure these constructs but there is no consensus (Ravitz, Maunder, Hunter, Sthankiya & Lancee, 2010; Hooley & Parker, 2006).

**Attachment.** The Adult Attachment Interview (AAI; George, Kaplan & Main, 1984, 1985, 1996), is generally considered the ‘gold standard’ measure of adult attachment, but can take several hours to conduct and score, consequently the time and resource constraints of this research, did not lend well to its use. There are a number of other instruments available and it is advised that researchers carefully consider the assessment measure that is most relevant to the attachment process they wish to study (Crowell, Farley & Shaver, 2008). Ravitz et al., (2010) recommend considering three key areas when selecting attachment measures as discussed below.

Firstly, the literature is divided on whether attachment styles are better measured using self-report or narrative methods and indeed whether these two methods are in fact assessing the same construct (Ravitz et al., 2010). Self-report attachment measures generally assess conscious processes such as thoughts, feelings and behaviours in the context of close relationships (Mikulincer & Shaver, 2007). One of the principle concerns regarding this type of measurement relates to whether people can accurately describe their behaviours and emotions. People may only be able to provide reflections on their conscious processes and might not be able to detect and therefore report on defences or unconscious processes that may be important (Crowell et al., 2008). Within the narrative tradition, measures such as the AAI assess aspects of

attachment behaviour that may lie outside an individual's conscious awareness and are therefore considered a more reliable measure. However, within this study consideration needed to be given to the limited resources available to the researcher along with minimising participant burden. The narrative tradition instruments usually require extensive training and take longer to administer and score. In this study, the attachment measure was being used with a number of other instruments and thus a measure that did not increase carer burden was important. It was agreed that a reliable, widely used, self-report measure was required to minimise burden whilst allowing for comparisons across the empirical literature.

The second consideration was whether to use a measure that assigned individuals to attachment *categories* or measured the degree to which *dimensions* of each style were present for an individual. Opinion is divided regarding whether adult attachment is categorical or dimensional (Ravitz et al., 2010), however categorical measures have been criticised for minimising individual differences and for their limited statistical power (when compared to dimensional counterparts) and dimensional measures are often preferred and recommended for research purposes (Bartholomew & Horowitz, 1991).

The final major consideration concerned the relationship of focus. In the infant literature, attachment is measured in relation to the primary caregiver, using behavioural observation measures such as The Strange Situation (Ainsworth, 1978). In the adult literature it is recognised that an individual may have a *general* adult attachment style (which is influenced by early caregiving experiences, Bowlby, 1982), but one can also have *specific* attachments to various individuals, such as a romantic partner, which can change over time and context (Ross & Spinner, 2001). For the purposes of this thesis, debate surrounded whether the measure needed to capture the attachment to the individual with psychosis, or whether it should capture a more general adult attachment style. The manner in which an individual responds to

caregiving is thought to be influenced by previous models of caregiving and care-receiving (Bowlby, 1969, 1982; Ainsworth, 1989; Sroufe, 1988). It was therefore considered important to understand the how a caregiver's *general* attachment style might influence caregiving responses as this is regarded as the more stable attachment 'state' (Cozzarelli, Karafa, Collins & Tagler, 2003) and thus the main influence over responses and cognitive appraisals.

Within the self-report tradition of attachment measurement, there are a number of measures available (Ravitz et al., 2010). However, many relate to adult romantic relationships, or parent-child dyads, which would not have been suitable for this research. The measure that was chosen (The Relationship Questionnaire, Bartholomew & Horowitz, 1991) met all the criteria specified above, being a dimensional, self-report measure of general adult attachment. A weakness however, was recognised to be the single-item assessment for each attachment style. It is acknowledged that multi-item self-report instruments are more reliable (Shaver, Belsky & Brennan, 2000). However, the measure has been widely used in the attachment literature and has good psychometric properties (Griffin & Bartholomew, 1994), thus was considered to be an adequate measure of attachment. To overcome some of these considerations and limitations, future research in this area would benefit from using the AAI. In addition, it would be useful to include a measure assessing different types of attachment, for example looking at general attachment and the specific attachment to the individual with psychosis.

**Expressed Emotion.** The Camberwell Family Interview (CFI, Brown & Rutter, 1966) is the 'gold standard' measure of EE. However, this measure requires 1-2 hours to administer and a further 2-3 hours to score per participant (Hooley & Parker, 2006). It was therefore not possible to use the CFI due to the high cost and time

intensity which would have resulted in increased burden on caregivers. The FMSS (Magana et al., 1986) is the most widely used alternative to the CFI and considered an excellent, reliable and validated measure for research purposes (Hooley & Parker, 2006). The FMSS only takes five minutes to administer and approximately 45 minutes to transcribe and score. It was agreed that this would be a suitable measure for assessing EE and would allow for comparison across studies in the wider literature body. I was trained and supervised by an expert rater and good inter-rater reliability was achieved.

One limitation of the FMSS is that the validated scoring is for the categorical constructs of high and low EE. More recently, it has been recognised that the constituent parts of EE (i.e. criticism and emotional over-involvement) may have different influences on caregiving outcomes (Barrowclough, Johnston & Tarrier, 1994). In designing the research, we were aware that it was important to differentiate between emotional over-involvement (EOI) and criticism, particularly as it was hypothesised that they may differentially relate to attachment styles. Therefore, in addition to the FMSS, it was agreed that a measure of EE would also be used that was validated to measure EOI and criticism. The Family Questionnaire (FQ; Wiedemann, Rayki, Feinstein & Hahlweg, 2002) has close concordance to the CFI and also provides a continuous scale of measurement. This was important for statistical reasons, as a continuous measure would be able to capture associations between EE and attachment. It was decided to keep both measures in the study in order to examine EE from both an observer-rated and self-report stance, due to the limitations associated with self-report measures (as briefly discussed above) and because the FMSS is a widely used measure and thus comparable in the wider literature.

## **Methodological Limitations: Recruitment**

It was agreed that recruitment should take place via Early Intervention Services (EIS), to ensure valid and reliable diagnostic criteria for service users (all diagnoses were confirmed by a psychiatrist). However, there were a number of limitations associated with this approach.

Having previously worked in an EIS, I approached the team lead and outlined the proposed research, receiving a positive initial response. There were a number of Trust-wide managerial and structural changes within the services at the time I was proposing my research and indeed throughout the entire recruitment phase. Although I had contact with one team lead, the team was part of a tri-borough service and I did not know the other teams or the newly appointed head of all three services. During initial discussions with the head of the tri-borough service, there was a concern that the services, clinicians and service users may already be over-burdened due to the high amount of concurrent research already taking place across the teams. Fortunately however, there was recognition that carers are an under-represented population in research in general (Mental Health Research Network, 2012), and also under-represented in the service I was recruiting from, as all the other ongoing research initiatives were related to service users. It was kindly agreed that I could recruit caregivers from all three EIS teams and local managers and clinicians were strongly encouraged to help with recruitment. Without this initial backing and ongoing support, recruitment would not have been possible.

There were a number of aspects to the recruitment method which may have led to potential bias. Ideally, all carers in the service would have been invited to take part in the research. However, I needed to recruit caregivers through the service users' care-coordinators due to ethical and practical reasons (for example care coordinators would know which service users on their caseload had a contactable caregiver). Relying on care-coordinators to recruit carers was challenging at times, and I had to

develop creative strategies to overcome obstacles during the recruitment process. Changes in staff meant that care coordinators did not always know which clients on their caseload had carers and thus the process of identifying potential caregivers was more challenging than expected. In addition, in line with Early Intervention Service protocols (NCCMH, 2014) clinicians carried out a great deal of community-based work, which meant several weeks might pass before I was able to arrange a meeting with a care-coordinator to discuss their caseload. Furthermore, clinical work understandably takes priority over research, and with a number of other research projects running concurrently, it was inevitable care-coordinators were not able to always prioritise my research. This meant that the process of recruitment spanned nine months. To overcome these difficulties, I found that spending entire days in each service (rather than scheduling one off appointments), was the most effective way to speak to care coordinators, remind them of the project and to follow up any potential carers that they may have discussed previously.

In addition, recruiting via care-coordinators meant that the initial invitation to take part in research was left to care coordinator discretion. Although care-coordinators were encouraged to invite *all* caregivers to take part, I noticed that clinicians might discuss ‘good’ potential candidates who were already engaged with the service. I recruited from each service in a step-wide fashion, spending time and embedding myself within each team, in order to build good relationships with staff. In each service I spent one or two days per week over a period of two-three months, before moving onto the next. It was noticeable that when I began recruiting from each team, there were a number of particularly interested staff members and carers at the outset, however recruitment became increasingly more difficult as the weeks progressed. I talked to team managers and care-coordinators about this issue and attempted to follow up even the ‘hardest to reach’ carers, however it was not always possible to reach these carers. As a consequence, the study might not have included

carers who were less engaged with services. Equally the study may not have reached those who were highly critical of clients and services (potentially with more difficulties in their attachment: Tait, Birchwood & Trower, 2002).

A further selection bias was language. The caseload across the entire three teams was in excess of 300 service users, however a limited number of these had identifiable and contactable carers. This number was further reduced by only including those carers who spoke English, as I did not have access to interpreting services. The area I was recruiting from had a large non-English speaking population, which meant that a considerable number of carers were excluded from taking part.

### **Personal Reflections: Working with Caregivers**

I had been informed that recruiting carers particularly in the early psychosis population was a notoriously difficult task. Whilst there were certainly challenges associated with recruitment and indeed a huge time resource involved, I was also impressed by the willingness of carers to spend their valuable and limited time contributing to research. Overall, I found that meeting with carers and collecting this data was an extremely rewarding personal and clinical experience.

I primarily met with carers in their homes after I had been introduced by care coordinators as a 'researcher' external to the team. This meant that carers were particularly open with me about their experiences and the service they had received from the EIS. It was clear that many carers I met wanted to be heard and informally told me they placed great value on our meeting and were grateful for research which focused on understanding caregiving process and experiences. Many carers wanted to talk about their caregiving journey and describe the difficulties or experiences they had been through. Occasionally this meant that carers displayed high levels of emotion, for example were very angry or upset about their experiences. I used my clinical skills to

manage the high emotions that often accompanied such discussions, aiming to respond to and manage concerns in a sensitive and appropriate manner for both carer and the early intervention teams. It was a key clinical skill to engage the carers in research whilst knowing my limitations in my role as a researcher, and not clinician. However at times it was very difficult to walk away from their homes, knowing the difficulties they were facing, and not being able to do more.

### **Summary**

From the conception of this thesis, experts in the field had informed me that recruiting carers in early psychosis populations was an ambitious task and successful recruitment was highly dependent upon the relationship with each individual service and care coordinators. At times, balancing the demands of data collection alongside clinical training was challenging. The data collection process was indeed time and energy intensive, compounded by the need to travel to early intervention services and carers' homes across three different outer-London boroughs in addition to the multiple structural, managerial, and staff changes taking place within each service at the time I was recruiting. However, the positive feedback from carers and their welcoming response towards research focused on caregiving, meant that for me, the data collection phase was the most rewarding aspect of completing this research. There are a number of limitations to this thesis relating to recruitment bias, assessment measures and methodological issues. However, it was truly a privilege to meet with carers, who are under-represented in the literature, to witness their experiences and contribute to a growing body of empirical evidence to further understand caregiving processes.

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## **Appendix 1.**

### **Ethical Approval**

**NRES Committee London - Fulham**  
Barlow House  
3rd Floor, 4 Minshull Street  
Manchester  
M1 3DZ

30 July 2014

Dr Miriam Fornells-Ambrojo  
Research Department of Clinical, Educational and Health Psychology, UCL  
4th Floor  
1-19 Torrington Place  
London  
WC1E 7HB

Dear Dr Fornells-Ambrojo

**Study title:** Can caregiving appraisals be understood using an attachment framework in early psychosis?  
**REC reference:** 14/LO/1252  
**IRAS project ID:** 144804

Thank you for your email of 30 July 2014. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 28 July 2014

**Documents received**

The documents received were as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Other [Email]		30 July 2014
Participant consent form	4.0- Tracked	30 July 2014

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

**14/LO/1252** Please quote this number on all correspondence

Yours sincerely



**Miss Katie Southead**  
**REC Assistant**

E-mail: [nrescommittee.london-fulham@nhs.net](mailto:nrescommittee.london-fulham@nhs.net)

A Research Ethics Committee established by the Health Research Authority

## **Appendix 2.**

### **Participant information sheets**

1. Invitation to participate in research
2. Participant information sheet

**Invitation to participate in research**

**Understanding Caregiving Relationships in Early Psychosis**

You are invited to take part in a research study being carried out within the Research Department of Clinical, Educational and Health Psychology at University College London (UCL) and West London Mental Health Trust.

The aim of this study is to improve our understanding of the relationship between an individual with psychosis (service user) and their carer. We know that these relationships can be very important to the service user and can provide them with a crucial source of support. We hope that by understanding relationship styles better, we will be able to improve the services we offer carers.

We are inviting **all** carers, which could be a parent, partner, sibling, close relative or close friend, of the service user within the Early Intervention Service (**EIS**) to take part. If you have been in a care-giving role for at least three months, and either live with the person you care for, or have at least 10 hours contact a week (either face-to-face or telephone), then you could be eligible to take part.

The study would involve **1 hour of your time** to complete some questionnaires about your experiences and beliefs as a carer. Your answers will be confidential and anonymised.

If you agree to take part, you will receive **£10 to compensate** for your time.

If you would like to know more about this study, please contact the Principal Investigator, Melanie Claxton on:

**[m.claxton@ucl.ac.uk](mailto:m.claxton@ucl.ac.uk)**

Alternatively, speak to a member of the EIS team, who can pass your contact details to the research team.

Yours Sincerely,

Early Intervention Team (EIS)  
West London Mental Health Trust

## Participant Information Sheet

Version: V2

Date: 26/06/14

REC REF:

### Understanding caregiving relationships in early psychosis

#### **What am I being asked to do?**

You are being invited to take part in a research study. Before you decide whether to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. The researcher will go through the information sheet with you and answer any questions you have. Please ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

#### **What is the purpose of the study?**

The aim of this study is to improve our understanding of the relationship between an individual with psychosis (service user) and their carer. The carer may be a parent, spouse, partner, sibling, relative or friend who is in close and regular contact with the service user. We know that these relationships can be very important to the service user and can provide them with a crucial source of support.

The study will specifically examine relationship styles and their importance to the caregiving relationship and certain caregiving beliefs and experiences. We hope that by understanding these relationship styles better we will be able to improve the services we offer carers and service users.

#### **Why have I been invited to take part?**

We have invited all carers of service users in the Early Intervention Service (EIS), to participate in the study. In order to take part, carers will need to have been caring for the service user for at least three months prior to the study and either live with the service user, or have at least three weekly contacts with the service user, totalling at least 10 hours (either face-to-face or telephone).

#### **Do I have to take part?**

*No. It is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. During the study, you are still free to withdraw at any time and without giving a reason and any data collected will be securely destroyed. A decision to withdraw at*

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*any time, or a decision not to take part, will not affect the standard of care you or the service user receive from the EIS in any way.*

**What will happen to me if I take part?**

Following your agreement to take part, Melanie Claxton, Trainee Clinical Psychologist, will invite you to complete some questionnaires that ask about care-giving experiences, relationships, mood and wellbeing. One of the questions is a 5-minute interview that is audio recorded. There are no right or wrong answers to the questions.

**When and where will the study take place?**

The study can take place at your home or at the EIS. The meeting will be agreed at a time that is convenient for you.

**How long will the study last?**

The meeting will last approximately one hour.

**Will you compensate me for my time?**

Yes. To compensate you for your time and travel, we will offer you £10.

**What are the possible risks of taking part?**

It is not expected that participation in this study will have any risks. However, if you find any of the questions asked upsetting and would like to talk about this, please talk to a member of the research team. The researcher will also have information on local resources and support services that you might find helpful.

**What are the possible benefits of taking part?**

By understanding more about care-giving relationships, we hope that this research will help to improve support services for other carers and service users who experience an episode of psychosis.

**Will my information be confidential?**

All of your answers to the questionnaires will be kept anonymously and will be identifiable only by a number, not by your name.

Your name will be kept separately, with the number, so that we can identify your questionnaires in the future if we need to (for example, if you decide you no longer want to be part of the study). We will only identify your questionnaires for a reason like this. The researchers will keep paper copies of questionnaires securely in a locked filing cabinet in a locked office. Audio recordings will be encrypted and password protected. Your details will be kept for up to 10 years, and then will be confidentially destroyed. We will keep a completely anonymised copy of the database indefinitely, from which you will not be able to be identified at all.

The information you give will usually be available only to the research team. However, should you give any information such as criminal disclosures, or information relating to your own or others safety, the research team will take appropriate action including passing on information to others.

**What should I do if I have any problems?**

If you wish to complain, or have any concerns about any aspect of the way you have been approached or treated by members of staff you may have experienced due to

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your participation in the research, National Health Service or UCL complaints mechanisms are available to you. Please ask the researcher if you would like more information on this.

In the unlikely event that you are harmed by taking part in this study, compensation may be available. If you suspect that the harm is the result of the Sponsor's (University College London, UCL) or the hospital's negligence then you may be able to claim compensation. After discussing with the researcher, please make the claim in writing to Dr Miriam Fornells-Ambrojo, who is the Chief Investigator for the research and is based at UCL. The Chief Investigator will then pass the claim to the Sponsor's Insurers, via the Sponsor's office. You may have to bear the costs of the legal action initially, and you should consult a lawyer about this.

If you would like further independent advice, you may contact West London Mental Health Trust Patient Advice and Liaison Service (PALS). Email: [pals@wlmht.nhs.uk](mailto:pals@wlmht.nhs.uk). Telephone: 0800 064 3330.

**Who is Organising and Funding the Research?**

Principal Investigator is Miss Melanie Claxton, of University College London (UCL), who will be working under the supervision of the Chief Investigator, Dr Miriam Fornells-Ambrojo, Clinical Psychologist and Juliana Onwumere, Clinical Psychologist. This study forms part of a doctoral thesis undertaken at UCL.

**What will happen to the results of the research study?**

The results of this research will be published as part of a doctoral thesis. The results may also be published in a scientific research journal. There will be no identifiable information included in any publication. If you would like a copy of any publications, please contact the Principal Investigator, Miss Melanie Claxton (details below).

**Who has reviewed the 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 XXX Research Ethics Committee.

**Who can I contact for further information?**

Miss Melanie Claxton, Principal Investigator  
Email: [m.claxton@ucl.ac.uk](mailto:m.claxton@ucl.ac.uk)

Dr Miriam Fornells-Ambrojo, Chief investigator  
Email: [miriam.fornells-ambrojo@ucl.ac.uk](mailto:miriam.fornells-ambrojo@ucl.ac.uk) Telephone: 020 7679 1218

Address: Research Dept of Clinical, Educational and Health Psychology, University College London, 1-19 Torrington Place, London, WC1E 7HB

**Thank you for taking part in this study.**

## **Appendix 3.**

### **Measures**

1. Caregiver Information Questionnaire
2. The Five Minute Speech Sample Script
3. The family Questionnaire (FQ)
4. The Brief Illness Perception Questionnaire (b-IPQ)
5. The Depression, Stress and Anxiety Questionnaire (DASS-21)
6. The Experience of Caregiving Inventory (ECI)
7. The Relationship Questionnaire (RQ)



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**Caregiver Information Questionnaire**

Participant ID.....

Please answer the following questions. Your answers will remain confidential.

**1. Gender:** Male  Female

**2. Date of Birth:** \_\_\_\_/\_\_\_\_/\_\_\_\_

**3. Please describe your ethnicity:**

White		Asian	
White British	<input type="checkbox"/>	Asian	<input type="checkbox"/>
White Other	<input type="checkbox"/>	Indian	<input type="checkbox"/>
<b>Black</b>		Pakistani	<input type="checkbox"/>
Black British	<input type="checkbox"/>	Asian Other	<input type="checkbox"/>
Black African	<input type="checkbox"/>	<b>Mixed Race</b>	
Black Caribbean	<input type="checkbox"/>	White and Black Caribbean	<input type="checkbox"/>
Black Other	<input type="checkbox"/>	White and Black African	<input type="checkbox"/>
		White and Asian / Other	<input type="checkbox"/>
		<b>Other (please specify)</b>	<input type="checkbox"/>

**4. Employment status:**

- Employed full-time
- Employed part-time
- Unemployed
- Homemaker
- Retired
- Student
- Other (please specify) \_\_\_\_\_

**5. Relationship status:**

- Single
- Married
- Cohabiting
- In a relationship but not cohabiting
- Divorced
- Widowed
- Other (please specify) \_\_\_\_\_

6. Do you have a 'confidante' or close friend that you can turn to for help?

Yes  No

7. How would you rate the quality of **your** relationship with the Early Intervention Service? (Please circle a number on the scale below)

0 1 2 3 4 5 6 7 8 9 10  
Very Neither good Very good  
poor nor poor

8. What is the gender of the person you care for?

Male  Female

9. What is the age of the person you care for? \_\_\_\_\_ Yrs

10. What is your relationship to person you care for:

I am the:

Parent   
Spouse/partner   
Sibling   
Friend   
child   
Other (please specify) \_\_\_\_\_

11. Do you live with the person you care for?

Yes  No

12. How many hours per week of face-to-face or telephone contact do you have with the person you care for? \_\_\_\_\_ Hours

13. How long have you been providing care for this person?

\_\_\_\_\_ Years \_\_\_\_\_ Months

14. Is the person you care for currently an inpatient?

Yes  No

14. How would you rate the mental health of the person you care for currently?

(Please circle a number on the scale below)

0 1 2 3 4 5 6 7 8 9 10  
Very Full  
unwell recovery

15. Do you have a care-giving role for anyone other than this person?

Yes  No

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**16. What is your relationship to the other person you have a caring for:**

- Parent
- Spouse/partner
- Sibling
- Friend
- child
- Other (please specify) \_\_\_\_\_

***Thank you for completing this questionnaire***



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### The Five Minute Speech Sample (FMSS)

The FMSS elicits a response from the patient's key relative / carer. The specific instructions given to the relative are:

*"I'd like to hear your thoughts about [the person you are caring] in your own words and without my interrupting you with any questions or comments. When I ask you to begin, I'd like you to speak for 5 minutes, telling me what kind of a person [he/she] is and how the two of you get along together. After you have begun to speak, I prefer not to answer any questions. Are there any questions you would like to ask me before we begin?"*



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### The Family Questionnaire

Participant ID.....

Date.....

This questionnaire lists different ways in which families try to cope with everyday problems. For each item please indicate how often you have reacted to the patient in this way. There are no right or wrong responses. It is best to note the first response that comes to mind. Please respond to each question, and mark only one response per question.

	Never / Very rarely	Rarely	Often	Very often
1. I tend to neglect myself because of him/her				
2. I have to keep asking him/her to do things				
3. I often think about what is to become of him/her				
4. He/she irritates me				
5. I keep thinking about the reasons for his/her illness				
6. I have to try not to criticize him/her				
7. I can't sleep because of him/her				
8. It's hard for us to agree on things				
9. When something about him/her bothers me, I keep it to myself				
10. He/she does not appreciate what I do for him/her				
11. I regard my own needs as less important				
12. He/she sometimes gets on my nerves				

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13. I'm very worried about him/her				
14. He/she does some things out of spite				
15. I thought I would become ill myself				
16. When he/she constantly wants something from me, it annoys me				
17. He/she is an important part of my life				
18. I have to insist that he/ she behave differently				
19. I have given up important things in order to be able to help him/her				
20. I'm often angry with him/her				



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**BRIEF ILLNESS PERCEPTION QUESTIONNAIRE**

Participant ID.....

Date .....

*For the following questions, please circle the number that best corresponds to your views:*

**1. How much do her problems/illness affect your life?**

0 1 2 3 4 5 6 7 8 9 10  
*No affect at all* *Severely affects my life*

**2. How long do you think her problems/illness will continue?**

0 1 2 3 4 5 6 7 8 9 10  
*A very short time* *Forever*

**3. How much control do you feel she has over her problems/illness?**

0 1 2 3 4 5 6 7 8 9 10  
*Absolutely no control* *Extreme control*

**4. How much do you think her treatment can help her problems/illness?**

0 1 2 3 4 5 6 7 8 9 10  
*Not at all helpful* *Extremely helpful*

**5. How much does she experience symptoms from her problems/illness?**

0 1 2 3 4 5 6 7 8 9 10  
*No symptoms at all* *Many severe symptoms*

**6. How concerned are you about her problems/illness?**

0 1 2 3 4 5 6 7 8 9 10  
*Not at all* *Extremely*

concerned

concerned

**7. How well do you feel you understand her problems/illness?**

0 1 2 3 4 5 6 7 8 9 10  
*Don't understand at all* *Understand very clearly*

**8. How much do her problems/illness affect you emotionally? (e.g. does it make you angry, scared, upset, or depressed?)**

0 1 2 3 4 5 6 7 8 9 10  
*Not at all affected emotionally* *Extremely affected emotionally*

Please list in rank-order the **three** most important factors that you believe caused her problems/illness

1. \_\_\_\_\_

2. \_\_\_\_\_

3. \_\_\_\_\_



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**DASS21**

Participant ID.....

Date.....

Please read each statement and circle a number 0, 1, 2 or 3 which indicates how much the statement applied to you *over the past week*. There are no right or wrong answers. Do not spend too much time on any statement.

*The rating scale is as follows:*

- 0 Did not apply to me at all
- 1 Applied to me to some degree, or some of the time
- 2 Applied to me to a considerable degree, or a good part of time
- 3 Applied to me very much, or most of the time

1	I found it hard to wind down	0	1	2	3
2	I was aware of dryness of my mouth	0	1	2	3
3	I couldn't seem to experience any positive feeling at all	0	1	2	3
4	I experienced breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion)	0	1	2	3
5	I found it difficult to work up the initiative to do things	0	1	2	3
6	I tended to over-react to situations	0	1	2	3
7	I experienced trembling (eg, in the hands)	0	1	2	3
8	I felt that I was using a lot of nervous energy	0	1	2	3
9	I was worried about situations in which I might panic and make a fool of myself	0	1	2	3
10	I felt that I had nothing to look forward to	0	1	2	3
11	I found myself getting agitated	0	1	2	3
12	I found it difficult to relax	0	1	2	3

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13	I felt down-hearted and blue	0	1	2	3
14	I was intolerant of anything that kept me from getting on with what I was doing	0	1	2	3
15	I felt I was close to panic	0	1	2	3
16	I was unable to become enthusiastic about anything	0	1	2	3
17	I felt I wasn't worth much as a person	0	1	2	3
18	I felt that I was rather touchy	0	1	2	3
19	I was aware of the action of my heart in the absence of physical exertion (eg, sense of heart rate increase, heart missing a beat)	0	1	2	3
20	I felt scared without any good reason	0	1	2	3
21	I felt that life was meaningless	0	1	2	3



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**EXPERIENCE OF CAREGIVING INVENTORY**

Participant ID.....

Date.....

The following statements commonly apply to persons who care for relative or friends with a serious mental illness. We would like you to read each statement and decide how often it has applied to you over the **PAST ONE MONTH**.

If it has **never** happened or **rarely** happened you would CIRCLE the number 0 or 1. If it has happened **sometimes**, then you would CIRCLE the number 2. If it has happened **often** or seems to have happened **nearly always**, then you would CIRCLE the number 3 or 4.

It is important to note that these are no right or wrong answers. Also it is best not to spend too long on any one statement. Often your first reaction will usually provide the best answer. While these seem to be a lot of statements, you will find that it won't take more than a moment or so to answer each one.

***During the past month** how often have you thought about:*

	NEVER	RARELY	SOME- TIMES	OFTEN	NEARLY ALWAYS
1. Your covering up his illness.....	0	1	2	3	4
2. Feeling unable to tell anyone of the illness.....	0	1	2	3	4
3. His difficulty looking after money.....	0	1	2	3	4
4. Having to support him.....	0	1	2	3	4
5. What life he might have had.....	0	1	2	3	4
6. His risk of committing suicide.....	0	1	2	3	4
7. I have learnt more about myself.....	0	1	2	3	4
8. I have contributed to others understanding of the illness.....	0	1	2	3	4
9. Being unable to do the things you want to do.....	0	1	2	3	4
10. How health professionals do not take you seriously.....	0	1	2	3	4
11. His dependence on you.....	0	1	2	3	4
12. Helping him to fill in the day.....	0	1	2	3	4
13. I have contributed to his wellbeing.....	0	1	2	3	4
14. That he makes a valuable contribution to the household.....	0	1	2	3	4
15. The effect on your finances if he becomes more seriously ill	0	1	2	3	4
16. Dealing with psychiatrists.....	0	1	2	3	4

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	<b>NEVER</b>	<b>RARELY</b>	<b>SOME- TIMES</b>	<b>OFTEN</b>	<b>NEARLY ALWAYS</b>
17. Him always being at the back of your mind.....	0	1	2	3	4
18. Whether you have done something to make him ill.....	0	1	2	3	4
19. That he has shown strengths in coping with his illness.....	0	1	2	3	4
20. I have become more confident in dealing with others.....	0	1	2	3	4
21. How family members do not understand your situation.....	0	1	2	3	4
22. That he is good company.....	0	1	2	3	4
23. I have become more understanding of others with problems..	0	1	2	3	4
24. How he thinks a lot about death.....	0	1	2	3	4
25. His lost opportunities.....	0	1	2	3	4
26. How to deal with mental health professionals.....	0	1	2	3	4
27. Feeling unable to have visitors at home.....	0	1	2	3	4
28. How he gets on with other family members.....	0	1	2	3	4
29. Backing his up when he runs out of money.....	0	1	2	3	4
30. How family members do not understand the illness.....	0	1	2	3	4
31. How he deliberately attempts to harm himself.....	0	1	2	3	4
32. I have become closer to some of my family.....	0	1	2	3	4
33. I have become closer to friends.....	0	1	2	3	4
34. I share some of his interests.....	0	1	2	3	4
35. I feel useful in my relationship with him.....	0	1	2	3	4
36. How health professionals do not understand your situation....	0	1	2	3	4
37. Whether he will ever get well.....	0	1	2	3	4
38. Feeling the stigma of having a mentally ill relative.....	0	1	2	3	4
39. How to explain his illness to others.....	0	1	2	3	4
40. Others leaving home because of the effect of his illness.....	0	1	2	3	4
41. Setting him up in accommodation.....	0	1	2	3	4
42. How to make complaints about his care.....	0	1	2	3	4
43. I have met helpful people.....	0	1	2	3	4
44. I have discovered strengths in myself.....	0	1	2	3	4
45. Feeling unable to leave him home alone.....	0	1	2	3	4
46. The effect of the illness on children in the family.....	0	1	2	3	4
47. The illness causing a family breakup.....	0	1	2	3	4
48. His keeping bad company.....	0	1	2	3	4
49. How his illness effects special family events.....	0	1	2	3	4
50. Finding out how hospitals or mental health services work.....	0	1	2	3	4
51. Doctor's knowledge of the services available to families.....	0	1	2	3	4
52. The difficulty getting information about his illness.....	0	1	2	3	4



**During the past month** how often have you thought about him being:

53. Moody.....	0	1	2	3	4
54. Unpredictable.....	0	1	2	3	4
55. Withdrawn.....	0	1	2	3	4
56. Uncommunicative.....	0	1	2	3	4
57. Not interested.....	0	1	2	3	4
58. Slow at doing things.....	0	1	2	3	4
59. Unreliable about doing things.....	0	1	2	3	4
60. Indecisive.....	0	1	2	3	4
61. Irritable.....	0	1	2	3	4
62. Inconsiderate.....	0	1	2	3	4
63. Behaving in a reckless way.....	0	1	2	3	4
64. Suspicious.....	0	1	2	3	4
65. Embarrassing in appearance.....	0	1	2	3	4
66. Behaving in a strange way.....	0	1	2	3	4



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**The Relationships Questionnaire**

Participant ID.....

Date .....

1. Below are four general relationship styles that people often report. Place a tick next to the description corresponding to the style that best describes you or is closest to the way you are.

<b>Style A.</b> It is easy for me to become emotionally close to others. I am comfortable depending on them and having them depend on me. I don't worry about being alone or having others not accept me.	
<b>Style B.</b> I am uncomfortable getting close to others. I want emotionally close relationships, but I find it difficult to trust others completely, or to depend on them. I worry that I will be hurt if I allow myself to become too close to others.	
<b>Style C.</b> I want to be completely emotionally intimate with others, but I often find that others are reluctant to get as close as I would like. I am uncomfortable being without close relationships, but I sometimes worry that others don't value me as much as I value them.	
<b>Style D.</b> I am comfortable without close emotional relationships. It is very important to me to feel independent and self-sufficient, and I prefer not to depend on others or have others depend on me.	

2. Now please rate each of the relationship styles to indicate how well or poorly each description corresponds to your general relationship style.

**Style A.** It is easy for me to become emotionally close to others. I am comfortable depending on them and having them depend on me. I don't worry about being alone or having others not accept me.

1                      3                      2                      4                      5                      6                      7  
Disagree                      Neutral/                      Agree  
Strongly                      Mixed                      Strongly

**Style B.** I am uncomfortable getting close to others. I want emotionally close relationships, but I find it difficult to trust others completely, or to depend on them. I worry that I will be hurt if I allow myself to become too close to others.

1                      3                      2                      4                      5                      6                      7  
Disagree                      Neutral/                      Agree  
Strongly                      Mixed                      Strongly

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**Style C.** I want to be completely emotionally intimate with others, but I often find that others are reluctant to get as close as I would like. I am uncomfortable being without close relationships, but I sometimes worry that others don't value me as much as I value them.

1                      3                      2                      4                      5                      6                      7  
Disagree                      Neutral/                      Agree  
Strongly                      Mixed                      Strongly

**Style D.** I am comfortable without close emotional relationships. It is very important to me to feel independent and self-sufficient, and I prefer not to depend on others or have others depend on me.

1                      3                      2                      4                      5                      6                      7  
Disagree                      Neutral/                      Agree  
Strongly                      Mixed                      Strongly

## **Appendix 4.**

### **Additional Tables**

1. Table 1. The association between expressed emotion and caregiving variables removing extra family members
2. Table 2. Associations between attachment style and caregiving variables removing extra family members
3. Table 3. Group differences between demographic variables and attachment and self-report EE scores
4. Table 4. Associations between continuous demographic variables and attachment and EE

Table 1.

Associations between expressed emotion and caregiving variables removing extra family members (N=36)

Caregiving Variables	Self-report EE				Observer-rated EE			
	Criticism ( <i>r</i> )	<i>p</i>	EOI ( <i>r</i> )	<i>p</i>	High EE (N=17), Mean (SD)	Low EE (N=19), Mean (SD)	<i>t</i>	<i>P</i>
Negative Caregiving Experiences (ECI)	<b>.51</b>	<b>.002**</b>	<b>.64</b>	<b>&lt;.001**</b>	101.6 (30.77)	84.79 (41.36)	1.40	.180
Distress (DASS-21) (n=39)	<b>.62</b>	<b>&lt;.001**</b>	<b>.49</b>	<b>.003**</b>	15.53 (7.96)	8.2 (7.83)	<b>2.75</b>	<b>.009**</b>
Caregiving Appraisals (b-IPQC) (n=40)								
Timeline	<b>.49</b>	<b>.02**</b>	.13	.447	6.29 (2.54)	5.53 (2.84)	0.85	.401
Personal control	-.24	.165	<b>-.45</b>	<b>.006**</b>	4.35 (2.69)	4.21 (2.96)	.151	.881
Emotional Representation	.29	0.08	<b>.72</b>	<b>&lt;.001**</b>	8.24 (1.86)	7.00 (2.98)	1.47	.150

Significant at \*p=0.05, \*\*p=0.01

Notes. ECI= Experience of Caregiving Inventory; DASS-21 = Distress, Anxiety Stress Scales; b-IPQC= brief-Illness perception Questionnaire. Attachment measured by FQ.

Table 2.

*Associations between attachment style and caregiving variables removing extra family members (N=36)*

Caregiving Variables	Attachment Style					
	Preoccupied- Anxious	<i>p</i>	Fearful- Avoidant	<i>p</i>	Dismissing- Avoidant	<i>p</i>
Negative Caregiving Experiences (ECI) (n=40)	.16	.339	.16	.353	.012	.946
Distress (DASS-21) (n=39)	.22	.208	<b>.43</b>	<b>.009**</b>	.000	.999
Caregiving Appraisals (B-IPQC) (n=40)						
Timeline	.07	.68	.19	.264	-.351	.061
Personal control	-.06	.731	-.14	.401	-.02	.916
Emotional Representation	.29	.09*	<b>.33</b>	<b>.050*</b>	.076	.658

Significant at \**p*=0.05, \*\**p*=0.01 (2-tailed for Pearson's *r*)

Notes. ECI= Experience of Caregiving Inventory; DASS-21 = Distress, Anxiety Stress Scales; b-IPQC= brief-Illness perception Questionnaire. Attachment measured by FQ.

Table 3.  
Group differences between demographic variables and attachment and self-report EE scores using independent t-tests

Demographic variables	Self-report EE				Attachment					
	Criticism		EOI		Fearful		Anxious		<i>Dismissive</i>	
	t	p	t	p	t	p	t	p	t	p
Gender (Male, female)	.77	.445	-1.23	.227	.98	.332	-.895	.377	-.435	.666
Ethnicity	.59	.561	-.48	.632	-1.03	.310	-.564	.576	-1.502	.142
Marital status	-.32	.750	-.110	.913	.66	.515	-.18	.855	.99	.33
Employment status	1.31	.200	1.99	.054	-1.58	.121	.135	.893	-1.32	.194
Parent / Non-parent	-.79	.432	.902	.373	.56	.577	1.15	.255	-1.70	.097
Living with Service user	1.32	.195	.817	.419	.567	.574	.042	.967	-.093	.927
Confidante	.535	.596	1.32	.195	1.15	.256	.82	.420	-1.20	.237

Table 4.

Associations between continuous demographic variables and attachment and EE using Pearson's correlation

Demographic variables	Self-Report EE				Attachment Style					
	Criticism (r)	p	Subjective EE EOI (r)	p	Preoccupied -Anxious (r)	p	Fearful- Avoidant (r)	p	Dismissing- Avoidant (r)	p
Caregiver Age	-.10	.544	.03	.882	.14	.399	.13	.442	-.13	.427
Duration of self-reported care-giving	-.24	.133	-.05	.811	-.074	.651	-.095	.558	.315	.47
Length in EIS	-.22	.290	-.15	.454	.17	.322	.13	.442	-.13	.427
Duration of self-reported care-giving	-.24	.133	-.16	.311	.30	.138	.24	.246	-.22	.291
S					.30	.138	.24	.246	-.22	.291