

VOLUME 1

EXPLORING FAMILY RELATIONSHIPS AND PSYCHOSIS

by

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Overview

This thesis is submitted in partial fulfilment of the requirements for the degree of Doctorate of Clinical Psychology (Clin.Psy.D.) at the University of Birmingham. The thesis consists of two volumes.

Volume 1

This volume comprises three chapters. The first, a systematic literature review of how positive relationships within families can support individuals experiencing psychosis. The second is a qualitative study investigating how families with one member with a first episode of psychosis have experienced their roles and relationships. The third chapter comprises a public domain briefing document which provides a plain language summary of the literature review and empirical paper.

Volume 2

Five Clinical Practice Reports (CPR) are presented in this volume. The first details the case of a 47-year-old woman with a moderate learning disability who was experiencing anxiety, formulated from Cognitive-Behavioural and Psychodynamic perspectives. The second is an evaluation of a community learning disability team's psychology challenging behaviour guidelines for staff working in residential homes. The third report is a single-case experimental design investigating the effectiveness of "Attentional Training" for a 72-year-old gentleman with health anxiety, drawing on a Cognitive-Behavioural model. The fourth report documents a case study of a 19-year-old male experiencing post-traumatic stress disorder, formulated within a cognitive framework. The fifth CPR is an abstract of an oral case presentation of an 11-year-old girl with a hypoxic-ischemic brain injury, comprising a detailed neuropsychological assessment and intervention recommendations.

Pseudonyms have been used throughout to ensure anonymity.

Dedication

For family.

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Completing this Doctorate would have been a hundred times harder without the wisdom, containment, inspiration and support of a few crucial people.

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Abbreviations

CFI	Camberwell Family Interview
EE	Expressed Emotion
EOI	Emotional Over-Involvement
FEP	First Episode of Psychosis
FES	Family Environment Scale
FMSS	Five Minute Speech Sample
IPA	Interpretative Phenomenological Analysis
LEE	Level of Expressed Emotion
SMI	Severe Mental Illness

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CHAPTER ONE

HOW DO POSITIVE FAMILY RELATIONSHIPS INFLUENCE INDIVIDUALS WITH PSYCHOSIS? A SYSTEMATIC REVIEW

Abstract

Background

Many theories abound describing the impact of environmental factors on mental health difficulties and psychosis in particular. While carer burden and the theory of Expressed Emotion (EE) discuss the influence of family relationships, these emphasise negative aspects and little is known about the effect of positive qualities. As national treatment recommendations endorse the efficacy of family therapeutic intervention, treatment protocols could benefit from a rounded understanding including the more positive elements of family environments.

Method

Literature published between 1946 and 2016 investigating positive influences that family relationships can have for the experiences of individuals with psychosis was searched using three databases. A total of 111 articles were screened for relevance. Data was extracted and synthesised, with rigorous quality assessment informed by Young and Solomon (2009) and Elliott, Fischer, and Rennie (1999), who detailed quality criteria for quantitative and qualitative research respectively.

Results

A total of 17 articles were identified with only one using qualitative methodology, the remainder used quantitative measures. Results clustered around five broad questions encompassing the construct of positive family environments: 1. Can family factors have a positive effect on service user outcome? 2. Who can help? 3. What constitutes a positive environment? 4. How can we recognise positive outcomes/environments? and 5. What factors can affect family functioning?

Conclusions

The articles suggested that positive family environments can significantly influence individual mental well-being. Clinical interventions that aim to modify family interactions could benefit from emphasising the cultivation of warmth and positive relations within families as a central part of their approach.

Introduction

Approximately half of all chronic mental health problems are reported to emerge by the mid-teen years, and three quarters by the mid-twenties (Kessler et al., 2007). Individuals within this age bracket predominantly live in the family home, and those who do not live with family members, often rely upon close relatives for support as non-familial relationships become more limited (Cresswell, Kuipers, & Power, 1992).

This review will focus upon the influence that the family environment has upon the development of individuals with psychosis. Consistent with recent guidelines, the term psychosis is preferred here, thereby reflecting how experiences such as paranoia and hearing voices, are commonly known (Cooke, 2014).

Family matters

As mental health services continue to commit to community care service provision (Mental Health Foundation, 2013), families are increasingly shouldering responsibility of caring for and supporting the recovery of loved ones with severe mental health difficulties. This equates to approximately 1.6 million carers of service users in the UK (Arksey et al., 2002; Carers UK, 2014). A 2015 survey (Carers UK) identified that 82% of carers experienced negative health consequences including increased stress, anxiety and depression. Carers are therefore more vulnerable to health difficulties than the average population (Carers UK, 2014). Given the invaluable contribution of carers on an individual and economic level, it is imperative that they are supported to protect their well-being.

Harrop and Trower (2001) suggest that schizophrenia develops commonly during adolescence as this is the most stressful time in the life cycle. They discuss how one of the key goals for adolescence is to develop autonomy. Parents help to nurture and guide this process in normal development, although typically conflict emerges as part of the struggle between parent and adolescent during this process. They also propose that familial support mediates distress experienced by the adolescent during this phase. In experiencing psychosis, many adolescents suffer an interruption in their expected developmental trajectory (Reed, 2008), potentially causing stress for both parents and their offspring. It also has implications upon developing relationships, family stress and threatens the ability to live independently (Harrop & Trower, 2001; Reed, 2008). It is therefore likely that the support of the family is required for on-going, more intensive input than was perhaps expected at this life stage, continuing into adulthood.

Stress

The stress-vulnerability (Zubin & Spring, 1977) and stress-reactivity (Myin-Germeys & Van Os, 2007) models propose that environmental stressors more severely impact those who are especially vulnerable or sensitive to stress, leading to psychiatric difficulties; consistent with studies identifying links between increased life stressors and schizophrenia (Phillips et al., 2006). Research also highlights associations between familial emotional reactivity to stress and vulnerability to psychosis. Lardinois, Lataster, Mengelers, Van Os, and Myin-Germeys (2011) found elevated sensitivity to stress associated with childhood trauma. They proposed that sensitisation resulted from early exposure to adversity and contributes to emotional and psychotic reactions to everyday stress.

The cognitive model (Garety, Kuipers, Fowler, Freeman, & Bebbington, 2001) attributes the impact of social marginalization or childhood trauma in creating negative schemas about the self and others. They hypothesised that externalising attributions are made in response to a triggering event as a result of biased reasoning. This model is popular in making sense of the maintenance of psychotic symptoms and interweaves well with the stress-reactivity model. It is perhaps limited by its neglect of the influence of family in the development of schemas and mediation of stressors. As families can mediate the impact of stressors (Harrop & Trower, 2001) are instrumental in modelling coping strategies (Bandura, 1971) and are part of the immediate environment it would be useful to consider the potential influence of families after someone has developed psychosis.

Family Influences

Caregiver burden and expressed emotion have been proposed to affect families' ability to cope with mental health difficulties and the interaction between patterns of relating and mental well-being.

Burden

Caregiver burden can be defined as adverse consequences on emotional, financial, social, physical and spiritual resources as a result of providing care for another person (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014). Supportive social networks and mental health service involvement are important in reducing subjective and objective burden of service users and their caregivers (Saunders, 2003). Family psychological distress contributes to burden and has been described as a significant predictor of family functioning (Saunders, 1999). Burden may therefore influence how the family relates to one another and the level of

baseline strain. In a study investigating resilience and strengths, caregiver burden overwhelmed the carer's ability to consider any positive aspects of their circumstances (Marsh et al., 1996). However this study did find resilience and even personal growth as a result of enduring difficult times. It is interesting to consider: if burden can detrimentally influence family relationships, what impact can positive attributes have?

Expressed Emotion

This prominent theory of influential family dynamics (Amaresha & Venkatasubramanian, 2012) describes EE as an environmental, psychosocial stressor that mediates the course of mental health difficulties. EE is measured by totalling the number of critical comments, hostility, emotional over-involvement (EOI), warmth and positive regard exhibited by a relative, commonly using the Camberwell Family Interview (Leff & Vaughn, 1985) although other assessment tools are sometimes used. Criticism, hostility and EOI contribute toward 'high EE' scores. Warmth and positive remarks characterise 'low EE' households. Families with high EE have more conflictual communication styles than families with lower EE (Amaresha & Venkatasubramanian, 2012). High EE essentially characterises a detrimental family environment that has been consistently associated with relapse in vulnerable individuals (Butzlaff & Hooley, 1998).

Research investigating these relationships has consistently associated risk of relapse with high EE (Butzlaff & Hooley, 1998; Amaresha & Venkatasubramanian, 2012) although inspection of this literature indicates that positive aspects of familial relationships have been neglected along the way. In fact, reflecting on the literature, EE assessment is limited in determining a rounded valuation of emotional milieu in several ways. Firstly, the assessment only

investigates the perceptions of a single relative. Each relationship is different and so it would be beneficial to identify for example, any counterbalancing relationships, or the overall milieu of the whole family, rather than just one individual. Secondly, it does not gather the service user's perception. It may be that the researcher's perspective differs from the individual who lives within that environment and has a deeper understanding of their relative's intentions. Additionally, the assessment is usually administered during a period of mental health crisis (Amaresha & Venkatasubramanian, 2012), inevitably when the patient is most unwell and the family under the most strain (Lauber, Eichenberger, Luginbühl, Keller, & Rössler, 2003). Therefore it is uncertain whether the assessment measures a trait of the relationship, or a potentially transient state related to carer burden. As 70% of critical comments emphasise negative symptoms, this may reflect attribution of symptoms to personality or motivation, rather than mental health difficulty (Amaresha & Venkatasubramanian, 2012). This raises the question of how much high EE reflects carer burden and frustration possibly related to misunderstanding of the illness.

EE is not a holistic method for understanding positive family relationships. Valuable information could be found in considering practical, emotional and financial support, family roles, dynamics and service user perceptions of the milieu.

The emphasis within the literature, upon negative familial relationships, through investigation of high EE, risks further stigmatising families and the development of a conflictual relationship between mental health services and families. It would be beneficial to provide some balance and focus on working collaboratively with families, recognising close bonds, support and positive contributions.

National Treatment Recommendations

NICE (2014) and NHS England (2015) guidance advises the timely provision of family therapy for families of those with psychosis, supported by a meta-analysis evidencing family intervention in effectively reducing relapse and hospital admissions (Pharoah, Jj, Rathbone, & Wong, 2010). NICE (2014) recommend that family therapy programmes include psycho-education, problem solving and crisis management, and in the main, family intervention models prioritise these as well as communication skills (Miklowitz, 2004). The rationale and aim being to alleviate negative patterns of relating and relieve burden; however the precise mechanisms attributable to effecting change remain uncertain (Miklowitz, 2004). Some good literature reviews have investigated family roles and functioning in severe mental health illness (Koutra, Vgontzas, Lionis, & Triliva, 2014; Miklowitz, 2004; Saunders, 2003), however they tend to focus on negative components with limited discussion of more constructive facets.

Given the relative paucity in research regarding the positive effects family members can have upon the well-being of individuals with mental health difficulties, it would be illuminating to gather the available evidence to gain a clearer understanding of the nature of their role. This information could inform and improve existing psychological interventions to encourage fostering the development of positive influences within families as part of routine clinical support.

Method

Research question

The aim of this review was to systematically search the literature base to identify positive influences that family relationships can have for the experiences of individuals with psychosis.

Review Method

Databases searched included: Embase (1974 – present); Medline (1946 – present) and Psychinfo (1967 – present). Searches were not limited by date of publication. Further methods of identifying suitable research involved examining the reference lists of relevant articles.

Search Terms

Keyword and subject heading searches were utilised, in conjunction with Boolean operators ‘*or*’ and ‘*and*’ as well as * to search word stems to identify relevant articles. See table 1. for details of search terms.

Table 1.

Keyword and Subject Heading Searches

Search Line	Construct	Search Terms
1	Positive Emotion	Positive affect Positive support Positive social Prosocial Emotional support Emotional climate Warmth Positive emotion All terms combined with 'or'
2	Family Relationships	Family interaction* Family environment Family factors* Home environment* Family support* Family attitude* Social function* Family function* Family cohes* Family relationship* Family adapt* Family caregiv* Family process* All terms combined with 'or'
3	Psychosis	Psychosis Psychotic Schizophrenia (all terms exploded) All terms combined with 'or'
4	Searches 1, 2 and 3 were combined with 'and'	

Terminology within the relevant research base commonly uses both psychosis and schizophrenia as a broad term. As indicated above, psychosis will be the preferred term in this review (BPS, 2014), however where authors specifically use the term schizophrenia, this will be reflected.

The following criteria were applied to ensure focus was maintained upon the research question and a minimum quality of returned articles.

Inclusion Criteria:

1. Studies published in peer reviewed journals.
2. Studies published in the English language.
3. Studies taking an empirical approach i.e. an experimental or observational methodology.
4. Studies that explicitly stated an aim to investigate positive influences or aspects of family functioning.
5. Studies associating positive family relational functioning with service user well-being.
6. Studies including individuals with Psychosis
7. Age of participants is not a factor that precludes any studies' inclusion

Exclusion Criteria:

1. Studies where the sole outcome measure is limited in determining a sensitive or meaningful measure of family relationships. Excluded studies include: medication compliance, IQ, and suicide rates alone.
2. Studies that do not include data about or focus on the service user.
3. Studies that focus on negative aspects of familial relationships e.g. burden, risk factors.
4. Studies considered to be taking a non-empirical approach i.e. summarising a purely theoretical position.
5. Studies primarily evaluating the outcome of a clinical intervention, with no examination of how family factors influence this outcome.
6. Studies that do not include service users with Psychosis.

Results

After duplicates were removed, 111 studies were identified. Screening for relevance took place via abstract review. 18 non peer-reviewed pieces were excluded (e.g. dissertation abstracts, conference abstracts); 31 were excluded for neglecting family aspects; 16 were excluded for irrelevance of mental health area (e.g. Autism, Alzheimer's disease etc.); 12 were rejected for using limited outcome measures (e.g. medication, IQ, suicide), four were not published in the English language, one did not take an empirical approach, six were reports of measurement tools; 10 focused solely upon negative influences of family members and four were intervention studies, not focusing upon the target construct. The remaining nine papers were included for review. A further eight articles were identified through reference lists and articles previously known to the author via initial and exploratory scoping exercises conducted while refining search terms using generic internet search engines.

A total of 17 articles were included in the review (see appendix A).

Descriptive Summary

Only one article used qualitative methodology, the remainder utilised a variety of quantitative approaches and included eight cohort, six cross-sectional and two case-controlled studies.

Key characteristics of the studies can be seen in the summary table presented in table 2.

below.

Table 2.

Key characteristics summary table

Reference	Focus/Aims	Methodology	Participant sample	Geographical location and setting	Analysis	Measures used	Main findings
Bentsen et al., (1998).	To predict demographic and clinical determinants of emotional warmth	Audiotaped interview rated for warmth and other variables discussed elsewhere for other study	47 SU ¹ s, 18-39 yrs, 60% chronic social security status (SSS), 19% illegal drugs. 72 key relatives.	Oslo, Norway	Non-parental relationships = higher warmth; SU job loss, drug use, threatened violence, food refusal = lower warmth; SU current job (or job loss with chronic SSS) and symptoms conceptual disorganisation, unusual thought content & social avoidance = higher warmth.	Camberwell Family Interview (CFI); Perceived Family Burden Scale (PFBS)	Spouses, cohabitantes & siblings = better relationships (free to leave?). Lifestyle/difficult behaviours related to drug abuse may harm relationships (or indicate more serious problems) Current job = less burden, job loss + chronic SSS legitimates illness - certified unwell = illness attribution related to warmth

¹ SU represents an abbreviation of Service User

Reference	Focus/Aims	Methodology	Participant sample	Geographical location and setting	Analysis	Measures used	Main findings
González-Pinto et al., (2011).	Positive & negative environmental factors & family history (FH) involved the development of Psychosis	Cross-sectional interviews	208 participants 9-17 years, 110 FEP, 98 controls. In/outpatients, participants recruited from hospitals, controls from schools/paediatric patients	Multi-centre, Spain	Higher FES positive subscales = protective effect, particularly intellectual-cultural & active-recreational orientations FES positive subscales = stronger protective effect for those with FH, especially cohesion, intellectual-cultural orientation & organisation	FES (relates to CFI) SU & parents completed interview Kiddie-Schedule for Affective Disorders and Schizophrenia, Present and Lifetime (K-SADS-PL)	Positive family environment associated with lower prevalence psychosis in predisposed participants Family environment particularly important where genetic risk for psychosis Mechanisms for action in positive/negative environmental factors different positive environmental factors may help vulnerable patients avoid disease progression in early life

Reference	Focus/Aims	Methodology	Participant sample	Geographical location and setting	Analysis	Measures used	Main findings
Greenberg, Knudsen, & Aschbrenner. (2006).	Parental warmth, praise & better relationship = higher life satisfaction = SU interactions that elicit positive responses	Mother 2 hour interview & self-admin Q SU - self-admin Q <3 weeks after mother interview	122 mother-child dyads, minimum weekly assistance with ADLs. Participant mothers more warm & better relationships than drop outs	Wisconsin, USA	3 pro-social constructs significantly correlated with SU life satisfaction. SU depressive symptoms = reduced life satisfaction. More close friends = better life satisfaction.	SU - Satisfaction with life SU - subscale Instrumental ADL scale (IADL) SU - friend count M - maternal warmth & praise ratings from 5 minute speech sample (FMSS) M - Positive Affect Index (PAI) M - Symptom severity scale	Life satisfaction = recovery oriented outcome positive parental appraisals & warmth important Parent ability to appreciate SU strengths reduces burden & increase SU QoL ² . 3 pro-social behaviours increase life satisfaction: 1. Activity initiation 2. Acknowledge & affirm small recovery steps 3. Less reactive to negative symptoms, accepting. Prosocial mothers separate person from illness, low prosocial = perceive wilful symptoms = angry
Greenwald. (1990).	Baseline family interaction predicts 3 year functioning	Cross-sectional observed or parental self-report measures. Family functioning and child ratings.	97 families of male offspring where 1 <u>parent</u> previously hospitalised for psychiatric difficulties inc. Schizophrenia, depression PD etc.	New York, USA Middle class	Activity/balance/warmth ratings predict child outcomes, communication predicts adaptive functioning	Observed family free play & Rorschach task; Adaptive functioning tests school/parent/clinician	Activity/balance/warmth in family interaction = good predictor of outcome. Family functioning contributes to pathological or optimal development

² QoL represents Quality of Life

Reference	Focus/Aims	Methodology	Participant sample	Geographical location and setting	Analysis	Measures used	Main findings
Guada, Hoe, Floyd, Barbour, & Brekke. (2012).	Family contact = direct positive effect on SU functioning	Cross-sectional, self-report scales of family contact and psychosocial functioning	94 SU/relative African American dyads, beginning treatment at local MH facility. Baseline measures taken before interventions	California, USA South Central LA, economically challenged area.	Increased family contact = increased SU psychosocial functioning Family pressure negatively impacts family resources & dysfunction. Family dysfunction negatively impacts SU psychosocial functioning	SU self-report number of contacts in previous 2 months & Role Functioning Scale	As family contact increases, consumer psychosocial functioning increases
Halford, Steindl, Varghese, & Schweitzer . (1999).	Impact of family affect regulation and positive/negative behaviours on relapse, symptoms	Baseline assessment measures plus 10 min recorded discussion (SU and relative) - non/ verbal +ve/-ve/neutral affect interactions coded.	52 families (parents or spouse) living with SU (FEP).	Queensland, Australia	Affect regulated families = lower relapse rates (more predictive than diagnosis), lower symptoms, better global functioning, better QoL, lower negative symptoms, no difference in negative/positive behaviour in non/relapsed Service users - behaviours not related to relapse,	BPRS, Global Assessment Scale (GAS), Premorbid Assessment Scale (PAS), QoL scale (QLS), Schedule Assessment negative symptoms (SANS) Interactional Coding System (ICS), Clinical Interview	Affect regulated relatives = more positive behaviours and lower negative behaviours. Patient behaviour or affect did not predict outcomes family affect regulation more predictive of outcomes than behaviours or diagnosis.

Reference	Focus/Aims	Methodology	Participant sample	Geographical location and setting	Analysis	Measures used	Main findings
Lebell et al., (1993).	SU outcomes mediated by perception of negative family relationships	Baseline measures completed when SU stable, outcomes evaluated for 1 year.	39 male o/p SUs, 67% non-white. 39 key relatives, 77% female, 20 mothers, 4 fathers, 7 siblings, 4 wives, 2 girlfriends, 1 aunt, 1 friend	USA	SU ratings of attitudes/feelings towards relatives and perceptions of relatives attitudes towards them significant predictor of outcomes	Brief Psychiatric Rating Scale (BPRS); Patient Rejection Scale (PRS); Dyadic Adjustment Scale (DAS), PBI (acronym not explained)	More frequent contact with relatives perceived to be benign protective factor
Lee, Barrowclough, & Lobban. (2014).	Warmth = reduced relapse EE ratings correlate with SU/family reported negative/positive affect SU reports positive affect = reduced relapse	Prospective, correlational. Baseline positive affect. 12 month relapse rates.	EIS & CMHT. 65 SU/key relative dyads. Community dwelling. 73% male SU, 76% mothers. 78% SU unemployed, 96% live with family.	North-west England, UK	Warmth predicts relapse @ 6 m, not 12. SU perceptions correlate with objective EE. SU perceptions positive affect from key relative= NO sig relationship relapse SU perceived positive affect from family = sig relationship relapse 6 & 12 months.	CFI, PANSS, Adapted 'care' subscale of Parental Bonding Instrument (PBI) & bespoke likert scales SU perceptions of negative/positive affect	Increased warmth & perceived positive family affect = reduced relapse @ 6 & 12 months. Su views of family more predictive than views of key relative positive family environments protective

Reference	Focus/Aims	Methodology	Participant sample	Geographical location and setting	Analysis	Measures used	Main findings
López et al., (2004).	Family attributions of SU control over illness, positive/negative affect associated with relapse	Dyads interviewed, audio recorded in previous study. Coded, correlational statistics & logistical regression.	98 SUs and key relatives, living together, 80% parents. 54 Anglo American (AA), 44 Mexican American (MA).	Southern California, USA.	High EOI group attributions of control = increased criticism & warmth but less relapse Low EOI group attributions of control = reduced warmth, increased criticism & relapse. Low EOI AA = attributions of control high warmth & criticism associated with relapse; Low EOI MA = low warmth & low family contact = relapse. Criticism not related to relapse in MA.	CFI, PAS, BPRS, Present State Examination (PSE)	Warmth = protective factor for MA but not AA Criticism = relapse in AA but not MA. Family values strong ties then lack of warmth = stressor, if family values independence then criticism = stressor. Attributions only marginally associated with outcomes, less so when control for meds and drugs.
O'Brien et al., (2006).	Critical comments = reduced social functioning, warmth, positive remarks & over involvement = reduced symptoms & improved social functioning (SF).	Baseline assessments plus CFI	26 SUs & relatives (81% mothers) living together	California, USA	Critical comments not associated with symptoms/SF Baseline warmth = improved SF correlation between positive remarks and SF Baselines positive remarks = improved negative & disorganised symptoms Baselines EOI = improvement in negative symptoms and SF.	CFI, Structured Interview for Prodromal Symptoms (SIPS), Strauss-Carpenter Outcomes Scale (SCOS), bespoke social functioning likert scale	Increased relative warmth, positive remarks and emotional involvement = reduced symptoms and better SF. EOI may be appropriate at different developmental stages Critical comments were about negative symptoms

Reference	Focus/Aims	Methodology	Participant sample	Geographical location and setting	Analysis	Measures used	Main findings
O'Brien et al., (2008).	Warmth, positive remarks & EOI correlate positively with relative constructive behaviour, relative constructive attitude & behaviours = improved symptoms/outcome	Dyads discuss meaningful event, recorded, coded for constructive/conflictual behaviour.	32 adolescent SU and caregivers.	California, USA	Caregiver positive remarks = increase caregiver constrictive behaviour No relationship between warmth & EOI positive remarks = decreased negative symptoms warmth = increased social functioning Caregiver behaviour does not predict symptoms/functional outcomes Sig reciprocity in constructive & conflictual behaviours	Family Interaction Task (FIT), CFI, SCOS, DSM IV prodromal symptoms scale.	Constructive attitudes = protective environment Relatives constructive participation increases SU constructive participation positive remarks & warmth positively impact SU warmth & interpersonal positivity = better social adjustment Tense atmosphere = risk symptom exacerbation Hereditary oversensitivity to stressful interpersonal interactions Critical attitudes without supportive attitudes = more pernicious
Schlosser et al., (2010).	EOI with warmth = better functioning @ follow-up	Baseline & 6-month follow-up symptoms & functioning related to EE, EOI & warmth. Low EE (42) participants selected to match high EE participants.	63, 12-35yrs prodromal or <3 months onset. Plus family member. 24 participants also in O'Brien's 2006 study.	California, USA	No sig. diff in SU perceived criticism & warmth in high/low EE families SU/relatives perceived criticism & warmth = NO influence on symptoms CFI rated warmth = not predictive positive symptoms Moderate interaction effect - moderate EOI + warmth = better functioning	CFI (mostly mothers), self-report perceived criticism & warmth (SU and carer), Scale of Prodromal Symptoms (SOPS), SCOS	Moderate EOI + warmth = protective factor. SU perceived family environment more influential than objective

Reference	Focus/Aims	Methodology	Participant sample	Geographical location and setting	Analysis	Measures used	Main findings
Smith & Greenberg. (2008).	Better relationship with SU sibling = sisters, no children, cohesive family. poor relationship where hurt/threatened, perceive control over symptoms.	Sibling self-administered questionnaire	136 siblings, some involvement in SU care. 55% female, average 44 years age, 4% ethnic, 52% college graduates.	Wisconsin, USA	Relationship quality not related to sibling children living at home, sister dyads not closer than others, cohesive families = better sibling relationships, poorer relationship when SU history violence, sibling fearful & perceived control. Siblings with personal gains from caring = closer more intimate relationship.	PAI, cohesion subscale of FES, y/n history SU violence/aggression, bespoke fears scale, Control attributions scale, adapted personal gains in coping, symptoms scale from Schizophrenia Outcome Module	Close childhood relationships = better quality relationship later. Single incidents of violence = profound consequences, siblings more informed re mental illness = may be less critical and perceive less control. Quality sibling relationship depends on earlier life experiences, appraisal of SU behaviour & perceived personal growth = major contributor to future involvement & QoL of SU adult.
Subandi. (2011).	To seek understanding of family EE in this cultural context	Monthly monitoring of families over 12-month period. Qualitative, Ethnographic approach	9 families. 3 highest EE families discussed in detail.	Yogyakarta, Central Java	Strong criticism, open hostility & over involvement can be interpreted as expression of love by SU. Criticism & warmth can co-exist - rapid expression & resolution Perceived boundary transgression different to observed due to cultural acceptability Important cultural concept of warmth & positive remarks as a way of dealing with adult in similar way to child = Ngemong = tolerant, uncritical, non-demanding attitude. Fulfilling SU needs.	Formal interviews, informal observation, Level of Expressed Emotion (LEE - Criticism, Irritability, Intrusiveness & lack emotional support). Adapted sentence completion test	High EE may not have negative effect when interpreted positively - meaning not just perception Culturally acceptable relative behaviour may be interpreted by SU as high EE Ngemong = pivotal to relapse prevention.

Reference	Focus/Aims	Methodology	Participant sample	Geographical location and setting	Analysis	Measures used	Main findings
Sun & Cheung. (1997).	How family function differs in un/remitting S families vs controls	Cross-sectional semi-structured interviews	120 caregivers, 1/3rd male, 2/3rds female. 64% parents, 15% siblings, 10% spouses	Hong Kong, day centres, outpatient clinics	Unremitting families = Less interest and care (affective involvement), poorer problem solving & communication skills, less able to fulfil instrumental & affective needs (roles) & less affective responsiveness	Family Assessment Device (FAD; self-report Q)	Unremitting families = poorer functioning; remitting families = same as controls Social support correlated with better family functioning
Tempier, Balbuena, Lepnurm, & Craig. (2013).	Larger network, higher perceived support & more family contact = longer remission Perceived support mediates no. hours contact, network size & longer remission	Retrospective, correlational cohort study. Family & social support variables related to remission	123, EI, non-affective psychosis. 1 month symptom free (from 144 RCT parent trial) 50% routine care, 50% in ACT EI model.	London, England, UK	Perceived emotional support = moderate inverse relationship with remission Perceived practical support not related to remission Hours contact = positive correlation with support & network size Perceived support most strongly related to network size Network size & hours contact mediated by perceived emotional support Network size & family contact support remission through effect on perceived emotional support	Clinical chart review, admission records, PANSS & GAF (acronym not explained) ratings Significant Others Scale (SOS)	Perceived social support predicts recovery Emotional aspect more predictive than provision of material needs Moderate correlation between perceived support & network size = structural & functional measures. Interdependent but not equivalent.

Reference	Focus/Aims	Methodology	Participant sample	Geographical location and setting	Analysis	Measures used	Main findings
Weisman, Rosales, Kymalainen, & Armesto. (2005).	Identify strengths of SUs and relatives who thrive emotionally despite S	Cross-sectional self-report scales and professional BPRS	57 relatives (40 female; 36 parents, 10 siblings), 47 SUs (23 males, 24 female)	Boston, LA & Miami; USA.	Increased perception of family cohesion = less DAS and general emotional distress in SUs and relatives, regardless ethnicity	BPRS, Depression Anxiety Stress Scale (DASS), Family Environment Scale (FES)	Family cohesion related to reduced general emotional distress (GED) in ethnic minorities but not Caucasians. Perception family unified & conducive= less depression & anxiety & stress. No difference in ethnicities and religiosity but attributed to scale rather than beliefs.

Six studies assessed the nature of family relationships using the Camberwell Family Interview (CFI, Leff & Vaughn, 1985). Other measures endeavouring to determine the same construct were derived from or validated against the CFI. These include the Five Minute Speech Sample (FMSS, Magaña et al., 1986), Family Environment Scale (FES, Moos, 1974), Level of Expressed Emotion (LEE, Cole & Kazarian, 1988), and Patient Rejection Scale (PRS, Kreisman, Simmens, & Joy, 1979). Other measures of family interaction included the Dyadic Adjustment Scale (DAS, Spanier, 1976), the Family Assessment Device (FAD, Epstein, Baldwin, & Bishop, 1983), and the Significant Others Scale (SOS, Power, Champion, & Aris, 1988). See table 3. for more details about the measures.

The CFI is a semi-structured interview conducted with a relative of the service user where the onset or exacerbation of the disorder, daily routines and emotional temperature of the household are discussed (Hooley & Parker, 2006). The interview takes one to two hours, is recorded and coded on five sub scales: criticism, hostility, EOI, warmth and positive remarks (Van Humbeeck, Van Audenhove, De Hert, Pieters, & Storms, 2002).

The aim of the articles varied from studies investigating what positive family factors may be involved in the development of psychosis to identifying factors likely to foster positive features in families. Outcome measures were also highly varied, some measured symptom remission, others prioritised social recovery.

Table 3.

Measures assessing family environment

Measure	Constructs measured	Format	Completed by
Camberwell Family Interview (CFI, Leff & Vaughn, 1985)	Family functioning	Audio taped interview. Coded.	Relative
Five Minute Speech Sample (FMSS, Magaña et al., 1986)	Quality of initial statement; Quality of relationship; Criticism; Emotional over involvement	Audio taped 5 minute interview. Coded.	Relative
Family Environment Scale (FES, Moos, 1974)	Relationship; Personal growth; Organisation and control.	90 item. True/False	Service User & Relative
Level of Expressed Emotion (LEE, Cole & Kazarian, 1988)	Expressed Emotion. Subscales: Intrusiveness; Emotional response; Attitude toward illness; Tolerance and expectations.	60 item. True/False	Service User
Patient Rejection Scale (PRS, Kreisman, Simmens, & Joy, 1979).	Critical; Hostile; Rejecting feelings toward service user	24 item. Likert scale	Relative
Dyadic Adjustment Scale (DAS, Spanier, 1976).	Dyadic satisfaction; Dyadic consensus; Dyadic cohesion; Affectional expression	32 item. Likert scale	Service User
Parental Bonding Instrument (PBI, Parker et al, 1979)	Parental care; Overprotection	25 item. Likert scale	Service User
Free Play (Cole et al, 1984)	Deviant/Healthy communication; Activity/Balance/Warmth	Observed family free play. Coded.	Whole nuclear Family
Consensus Rorschach (Loveland, Wynne & Singer, 1963)	Deviant/Healthy communication; Activity/Balance/Warmth	Observed family task. Coded.	Whole nuclear Family
Family Assessment Device (Epstein, Baldwin, & Bishop, 1983)	Problem solving; Communication, Roles, Affective responsiveness, Affective involvement, Behavioural control, General functioning	60 item. Likert scale.	Relative
Significant Others Scale (SOS, Power, Champion, & Aris, 1988)	Perceived availability of support, function of support, quality of support	10 item. Likert scale.	Service User
Interactional Coding System (ICS; Hahlweg & Conrad, 1985)	Self-disclosure; Positive solutions; Acceptance; Agreement; Problem description; Meta-communication; Listening; Criticise; Negative solution; Justification; Disagreement; Other.	Videotaped discussion. Coded.	Service User & Key Relative

Quality Review

Methodological quality was assessed using Young and Solomon's (2009) critical appraisal criteria for quantitative research, and Elliott, Fischer, and Rennie's (1999) guidelines for qualitative research. As discussed by Greenhalgh (2014), checklists of this nature can be very helpful in evaluating study quality, however each criterion may have a more or less significant impact upon the overall appraisal. As such, judgement also played a role in determining the overall quality rating. Supervision was used to ensure rigorous standards were consistently applied during this more qualitative aspect of evaluation. The aim of the quality review was to evaluate the evidence reported in the studies determining the influence of positive family factors on individual service user mental well-being.

A graded quality evaluation system was devised to highlight good, medium and poorer quality studies, using a traffic light classification scheme (see table 4.). Nine studies were awarded a good quality classification, indicated by the colour green. This indicated that the studies were considered to be methodologically robust. Any methodological flaws or information not provided, indicated by amber or red colourings, were considered reasonable or unavoidable given the clinical settings of the research and were not of a compromising nature. Seven studies were assigned a medium quality grade, indicated by the colour orange. This indicated that while there were some methodological flaws which required consideration, these were not of sufficient severity to endanger the interpretation of the results. Only one study by Greenwald (1990) was assigned the colour red to signify poor quality methodology; indicating a collection of serious methodological flaws which may compromise the conclusions drawn from it. Such issues included inadequate description of assessment measures used, poor detail, and questionable reliability and validity of assessment tools. The

designation of individuals to an 'at risk' state was assigned by a considerably loose definition, by modern standards and one-third of participants were lost to follow-up while the authors made no consideration of attrition bias.

Table 4.

Quality summary

Cross-sectional Studies	Relevant question?	Contribution to knowledge	Appropriate design	Methodology addresses bias	Adhered to original protocol	Hypothesis tested	Correct statistical analysis	Data justifies conclusions	Conflicts of interest	Sample clearly defined?	Representative sample?	Exposures, confounders, outcomes measured accurately?	Range of US severity assessed?	Quality score	Notes
Bentsen et al., (1998).	Yes	Yes	Yes	No Key/relative substance abuse reported.	No. Not discussed	Yes	Yes	Partial *Total scores not significantly correlated but items from them were. *Small numbers	No	No	Yes 80% of patients admitted to two hospitals, good rate of participation	No. Low inter-rater reliability (0.45) in acute episode or relapse.		Some methodological flaws to be considered but do not undermine results	
Greenberg, Knudsen, & Aschbrenner (2006).	Yes	Yes	Yes	Yes Objective measures taken. Attrition bias investigated and discussed.	No Participants recruited mid-way through project and did not complete measures	Yes	Yes Incorrect qualitative analysis/reporting though	Partial *Claims parental but omits fathers. Brief qualitative method not discussed. *Some participants didn't complete crucial measures: warmth & praise.	No	Yes	No High (40%) dropouts.	Yes Tendency for participants to have better relationships & higher warmth than dropouts.	No Inadequately discussed. Only figures for no hospitalisations given		Some methodological flaws to be considered but do not undermine results
Guadaño-Hoie, Floyd, Barbour, & Brekke (2012).	Yes	Yes	Yes	No Relative completed scales of family pressure & dysfunction	No Not discussed	Yes	Partial Underpowered and problems of collinearity	Partial See previous criterion	No	Yes Missing detail regarding severity of illness	Partial No disclosure of participants approached or dropped out	Partial Confounding factors not discussed and outcomes generally self-report	No Not discussed		Some methodological flaws to be considered but do not undermine results
López, Polo, Karno, Hipke, Jenkins, Vaughn, & Snyder (2004).	Yes	Yes	Yes	Partial Detection of bias as tested & stated. Hypotheses and excluded participants who did not change over time. Higher EE scores chosen when two relatives interviewed	Yes. Reexamination of field study data	Yes But other unstated hypotheses well.	Yes	Yes Some findings overstated but main findings substantiated	No	Yes	Partial No disclosure of participants approached.	Yes	No Not discussed		Robust methodology. Any flaws considered reasonable and do not compromise results
Smith & Greenberg (2008).	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes. 27% approached did not participate.	Yes	No Not discussed		Robust methodology. Any flaws considered reasonable and unavoidable and do not compromise results
Weisman, Rosales, Kymalainen, & Armesto (2005).	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Partial Not all conclusions made were grounded in data researched in article	No	Yes	Partial No disclosure of participants approached.	Partial Issues with reliability estimates in SES.	No Not discussed		Robust methodology. Any flaws considered reasonable and unavoidable and do not compromise results

Cohort Studies	Relevant question?	Contribution to knowledge	Appropriate Design	Methodology addresses bias	Adhered to original protocol	Hypothesis tested	Correct statistical analysis	Data justifies conclusions	Conflicts of interest	Prospective / retrospective	Representative of defined group?	Confounding factors identified?	Exposures, confounders, outcomes measured accurately?	Losses to follow-up?	Follow-up sufficiently long?	Quality score	Notes
Greenwald, (1990)	Yes	Yes	Yes	No Selection bias likely as participants limited to intact, middle class families.	No Not discussed	Yes	Yes	No	No	Prospective	No	No Serious inter-rater reliability issues	No Inadequate measurement of risk status	Yes 67% discussed about why. No disclosure of participants approached	Yes 3 years.	Red	Several serious methodological flaws which compromise liability and validity of results
Halford, Steindl, Varghese, & Schweitzer (1999)	Yes	Yes	Yes	No Detection bias as low number of participants	No Not discussed	Yes	Partial Limited number of participants for depth of analysis	Yes	No	Prospective	Partial Diagnoses include schizophrenia, depression, bipolar & other	Yes	Yes	Yes Well discussed. No disclosure of participants approached	Yes 6 months.	Green	Robust methodology. Any flaws considered reasonable and unavoidable and do not compromise results
Lebell (1993)	Yes	Yes	Yes	Partial No attempt to control counterbalance hostile symptoms	No Not discussed	No Not disclosed	Yes	Yes Because the conclusions were suitable tentative.	No	Prospective	No Only males included	No	Yes	No None disclosed. No disclosure of participants approached	Yes 1 year	Green	Robust methodology. Any flaws considered reasonable and unavoidable and do not compromise results
Lee, Barrowclough, Lobban (2014)	Yes	Yes	Yes	Yes	No Addition of preexisting study	Yes	Yes	Yes	No	Prospective	Partial Unsure level of contact	No	Yes	Yes Inadequate relapse info, No disclosure of participants approached	Yes 1 year	Green	Robust methodology. Any flaws considered reasonable and unavoidable and do not compromise results
O'Brien (2006)	Yes	Yes	Yes	No Significant attrition	Yes	Yes	Partial Low numbers for statistical analysis (26)	Yes	No	Prospective	Yes	No	Yes	Yes Only 0% of sample invited. 60% did not take part fully. No discussion.	Partial 3 months	Orange	Some methodological flaws considered but do not undermine results
O'Brien (2008)	Yes	Yes	Yes	No Significant attrition, no discussion. Unclear whether participants were included in previous study.	Yes	Yes	Partial Low numbers for statistical analysis (32)	Yes	No	Prospective	Yes	No	Yes	Partial 37% response rate, 20% participants dropout in discussion	Partial 4 months	Orange	Some methodological flaws considered but do not undermine results
Schlosser et al. (2010)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Prospective	Yes	No	Partial Family member reported warmth	No Not reported.	Yes 6 months	Green	Robust methodology. Any flaws considered reasonable and unavoidable and do not compromise results
Tempier, Balbuena, Lepnum, & Craig (2013)	Yes	Yes	Yes	No Did not address different treatment arms of parent study. Only used patients in remission. 'symptom free 1 month'	Yes	Yes	Yes	Yes	No	Retrospective	No Only selected those in remission	No	No Treatment not discussed, confounders not discussed	Yes Participants not in remission, No disclosure of participants approached	Yes 18 months	Orange	Some methodological flaws considered but do not undermine results

Case-control Studies	Relevant question?	Contribution to knowledge	Appropriate design	Methodology addresses bias	Adhered to original protocol	Hypothesis tested	Correct statistical analysis	Data justifies conclusions	Conflicts of interest	Cases clearly defined?	Cases representative of defined population?	Controls from same population as the cases?	Study measures identical for cases and controls?	Study measures objective? Recall bias likely?	Quality score	Notes
González-Pinto et al., (2011).	Yes	Yes	Yes	Partial Possible detection bias	No Not discussed	Yes	Yes	Yes	No	Yes	Partial No disclosure of participants approached, low drop-out rate (11%)	No Schools & Pediatric clinics	Yes	Yes Both objective and subjective data	High	Robust methodology. Any flaws considered reasonable and do not compromise results
Sun, & Cheung, (1997).	Yes	Yes	Yes	No Family member opinion regarding symptomology	Yes	Yes	Yes	Yes	No	Yes	Partial 22% response rate, no discussion. Wide age range, typical gender balance	No 1st year students, very different characteristics	Yes But collected differently structured interview vs self-report	Partial Subjective, possible bias in interview	Low	Some methodological flaws to be considered but do not undermine results

Qualitative Study	Scientific context & purpose a relationship of study to literature is clear?	Appropriate research methods	Respect for participants (Informed consent, ethics)	Specified methods	Appropriately tentative discussion of implications	Clarity of writing/presentation	Contribution to knowledge	Owning perspective (Authors theoretical orientations and personal anticipations, recognise values, interests, assumptions & role plays in understanding)	Situated sample (describe life circumstances of participants - gender, age, ethnicity, class)	Grounded in examples (e.g. to illustrate analytic procedures comparing more equal perspectives)	Coherent Data organised to form a map, framework or underlying structure.	General vs. specific research tasks General understanding based on appropriate range of participants/situations. Specific understanding described systematically	Resonated with readers Data presented in way that reader agrees it is accurate	Quality score	Notes
Subandi, (2011).	Yes	Yes	No	Yes Procedures specified No Method of analysis not discussed	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes But no discussion of limitations	Yes	Low	Some methodological flaws to be considered but do not undermine results

Common methodological limitations included the risk of unreliable assessment of dependent variables and outcomes due to the use of family member self-report of service user drug use, symptomology or family relationships. Family members do not always understand that negative symptoms can be symptoms of illness and not negative attributes of the individual's personality. They may not be aware of the extent of their loved one's drug use, and crucially, their opinion on the family environment may differ significantly from the service user, or other members of the family. Often, family environment was assessed via the relationship between two family members, however this risks neglecting the influence of other important relationships. This could have been improved by a more 360-degree assessment approach, including objective measures, service user reports and other involved parties.

Additionally, twelve studies did not report the numbers of participants that were approached while four reported a high dropout rate with limited or no discussion of the characteristics of the dropouts (see table 4, Quality Summary). This is particularly important when studying the relationships between family members as willing participation in their loved one's care may represent a significant indicator of the quality of the relationship. It is a common feature in this kind of research that the most difficult participants to access could reveal important differences compared to those with perhaps more support. As a result, it may be that families identified in studies as having poorer relationships, are still relatively positive compared to those who chose not to take part. Therefore, the groups may not be as disparate as assumed thus limiting the effectiveness of statistical analysis. Studies that described the characteristics of the dropouts were in a better position to assess this risk.

Broadly, the studies used participant samples from a range of pools including at risk and prodromal samples, hospital, and outpatient settings. This may enhance the generalisation of their findings due to methodological strengths in ecological validity as their participants reflect typical clinical settings.

Although the CFI is known as the ‘gold standard’ (Hooley & Parker, 2006) tool for the measurement of EE, it has some qualities which bring into question its ability to assess the emotional climate of the home environment. Further to the limited perspectives measured as already discussed, the questions in the schedule are rather biased toward negative aspects of the relationship with little room for discussion of beneficial qualities. This limits possible scores on the positive subscales: warmth and positive remarks. Therefore it is perhaps not the most accurate reflection of the spectrum of favourable relationship factors. Scales based upon the CFI are also vulnerable to these limitations.

The variability in the quality of the studies cautions the reader to carefully consider the generalisation of the findings. Indeed, even high quality studies may not necessarily be able to make conclusions applicable to individuals in other cultures and different circumstances (Singh, Harley, & Suhail, 2013).

How Do Positive Family Relationships Influence Individuals with Psychosis?

1. Can family factors have a positive effect on service user outcome?

A large proportion of articles investigated the extent to which family factors can have a positive effect on service users' well-being. As such the outcomes of different family environments are considered here. Factors identified as components of positive family environments are detailed. The outcomes of the relevant studies are grouped according to these possible positive components.

Fourteen studies assessed service user functioning and outcomes, comparative to different components of qualities assumed to represent good family functioning.

Warmth

Eight studies investigated the effect of family warmth on service user outcome. A total of seven studies reported a positive effect of warmth on outcome (Greenberg, Knudsen, & Aschbrenner, 2006; Greenwald, 1990; Lee, Barrowclough, & Lobban, 2014; López et al., 2004; O'Brien et al., 2006, 2008; Subandi, 2011) and only one reported to the contrary (Schlosser et al., 2010).

Of the seven studies, three can be further divided as those that used the CFI to measure young people either at risk of, or during their first episode of psychosis (Lee et al., 2014; O'Brien et al., 2006, 2008). The more methodologically robust article (Lee et al., 2014), found significant associations between increased warmth and reduced relapse rates at six and 12 months in 65 adolescents experiencing their First-Episode Psychosis (FEP) and their families. Overall EE status and components such as critical comments were not found to be associated

with relapse at 12 months. The remaining two articles (O'Brien et al., 2006, 2008) identified similar associations between warmth and outcome in terms of improved social functioning, however both were limited by short follow-up time periods (three and four months respectively) and low numbers of participants (26 and 32).

Of the remaining articles Greenwald (1990) will not be discussed in detail here due to serious quality issues that were raised in the quality review chapter.

Greenberg, Knudsen, & Aschbrenner (2006) used the FMSS to assess 122 adult parent-child relationships and similarly found an important association between warmth and service user outcome measured as life satisfaction. The remaining articles further support this hypothesis and are discussed in more detail in chapter 3.

Interestingly, the only study to find no significant correlation between warmth and outcome (Schlosser et al., 2010), did identify a significant interaction between warmth and EOI which will be discussed in more detail later.

Overall, the studies that attempted to quantitatively determine the influence of family factors on outcome were frequently limited by small quantities of participants and as such we must be cautious in our interpretation of them. However, the balance of evidence appears to tip in favour of those suggesting that family warmth can be of benefit to the individual experiencing mental health difficulties.

Family Contact

Four studies measured family functioning through quantity of contact. Unfortunately it was not well reported how this information was obtained, from whom and over what period of

time. Three studies found that increased family contact was related to more positive service user outcomes (Guada, Hoe, Floyd, Barbour, & Brekke, 2012; Lebell et al., 1993; López et al., 2004), and only one study did not identify any effect (Tempier, Balbuena, Lepnurm, & Craig, 2013).

Lebell et al. (1993), López et al. (2004) and Guada, Hoe, Floyd, Barbour, and Brekke (2012) all concluded that their ethnically diverse samples (“non-white”, Mexican American and African American respectively) benefitted from increased family contact. However, it is difficult to disentangle the effects of family environment as both samples noted that other family factors such as warmth and affective involvement also influenced service user outcome. Although the studies were generally considered to be methodologically robust, difficulty with determining the quality of the Guada et al. (2012) study was due to inadequate detail in reported procedure.

Tempier, Balbuena, Lepnurm, and Craig (2013) on the other hand reported that family contact itself did not differentiate between participants with more or fewer days of symptom remission, however contact was related to perceived emotional support which was then related to improved relapse rates. They concluded that the key operator of familial contact is through social, emotional support.

Overall, perhaps the literature points toward a positive effect of family contact on service user outcomes, however it is not clear through what mechanisms this may operate. It is suggested that family contact functions as a by-product of a beneficial family relationship, however conclusions would benefit from more supporting evidence.

Positive remarks and behaviours

Further to findings supporting warmth as a positive influence, O'Brien et al. (2006, 2008) also identified the benefit of family positive remarks on negative symptoms and social functioning. They found that increased positive remarks were correlated with the exhibition of constructive behaviour during a family interaction task, which was then correlated with reciprocal constructive behaviour from the offspring. The authors suggest that constructive attitudes may indicate skilful interpersonal environments. Similarly Greenberg, Knudsen, and Aschbrenner (2006) also found a positive effect of maternal praise on life satisfaction in adults with schizophrenia.

Conversely, two studies did not corroborate these findings. Halford, Steindl, Varghese, and Schweitzer (1999) and Yu-Kit Sun and Cheung (1997) found no difference in relative or patient behaviours associated with patient outcome. Some methodological concerns were noted in the latter study however, as family member opinions were used to collect symptom outcome data, the reliability and validity of this method were unsubstantiated. On balance, although there is a suggestion that positive family remarks may positively influence outcome, the evidence is limited at this time.

Family Positive Affect

It is possible that family positive remarks are reflective of constructive attitudes and adaptive attributions regarding a loved one's illness. This potentially then results in a more supportive and recovery-oriented environment.

According to Gottman (as cited in Halford et al. 1999), when all individuals exhibit more positive than negative or neutral affect, the overall dynamic is 'affect regulated'. Greenberg et al. (2006), Halford et al. (1999) and Lee, Barrowclough, and Lobban (2014) found that praise, affect regulation and perceived positive family affect increased service user life satisfaction and protected against relapse at follow-up and in Lee et al.'s (2014) article, positive affect correlated with warmth. These studies appear to show that positive affect has a beneficial impact on outcome, however they do not reveal much about the underlying processes.

Attribution theory, as described by Barrowclough and Hooley (2003) posits that low EE relatives hold a good understanding and recognition of the individuals' symptoms as illness related and are less likely to believe that the service user has control over it. Attitudes characteristic of high EE reflect beliefs that aspects of service users' behaviours are unfavourable and controllable. Much research (see Barrowclough & Hooley, 2003 for a review) has been dedicated to testing the relationship between attributions, critical attitudes, comments and patient well-being. This is not a review of attribution theory, however one study did explore the phenomenon as a potential explanation behind family affect, EOI and outcome.

López et al. (2004) did not find reliable effects of attributions of control with negative affect and higher relapse. Conversely, a trend was found in high EOI families relating perceptions of control with increased warmth and reduced relapse. Conclusions regarding attribution theory are not considered robust here due to the weak statistical outcomes.

While the evidence may lead us to believe that positive affect supports mental well-being, it is still unclear by what means.

Affective Responsiveness/Emotional Over Involvement

The EE literature discusses the negative impact of EOI on service user well-being (Amaresha & Venkatasubramanian, 2012). However, the articles in this review reconceive emotional or affective involvement as positive and even appropriate in certain circumstances.

Five studies discussed how optimal levels of affective involvement could support the individual. Three (O'Brien et al., 2006; Schlosser et al., 2010; Yu-Kit Sun & Cheung, 1997) identified a protective effect of affective involvement, whereas two (López et al., 2004; O'Brien et al., 2008) provided a more mixed picture, finding a combination of significant and non-significant associations.

O'Brien et al. (2006) and Schlosser et al. (2010) studied American adolescents either at risk, experiencing prodromal symptoms or recent onset of psychosis using the CFI. They found an association between higher levels of emotional involvement, improved negative symptomology and social functioning at follow-up. The authors suggest that this may reflect age-appropriate levels of emotional involvement, rather than EOI. It should be noted that both reports indicated the same trend however shared one third of the participants. Yu-Kit Sun and Cheung (1997) recruited a Chinese adult sample and found that families of patients with unremitting schizophrenia exhibited poorer affective involvement. Unfortunately without performing discriminant analyses it is difficult to distinguish between the effects of the diverse dimensions measured.

O'Brien et al. (2008) conversely, found no correlation between EOI and patient symptom or functional outcome. Their results were limited by the small participant group and the short outcome period of only four months. Furthermore a high dropout rate of 20% was reported without discussion of the impact this may have on the characteristics of the remaining participants, thus increasing the risk of attrition bias. As mentioned previously López et al. (2004) found that high EOI families perceiving service user control over their symptoms were associated with increased warmth and reduced relapse, whereas the opposite pattern was found for low EOI families. Although the impact of positive affective involvement may hold promise for future investigation, at present there is insufficient evidence to enable us to come to a conclusive decision with regards to impact upon outcomes.

Cohesion

Two studies assessed the effect of family cohesion on outcome in adults using the FES assessment measure (González-Pinto et al., 2011; Weisman, Rosales, Kymalainen, & Armesto, 2005). The participants were diverse: from Spanish, Latino, African American, and White backgrounds. Both studies found consistent associations between increased family cohesion and improved well-being. Weisman et al. (2005) divided their sample and found that service users from all backgrounds benefitted from perceived cohesion, while family members from minority backgrounds benefitted more than their Caucasian counterparts. One limitation of this study however, was the small numbers of participants with each group only yielding 21 or fewer individuals.

González-Pinto et al. (2011) provide stronger methodology, and also found associations of improved outcome with “intellectual-cultural orientation and active recreational orientation”, however further studies are yet to be found that investigate these factors.

2. Who can help?

Most research focused upon service user relationships with key relatives, usually mothers. Perhaps this reflects the cultural norm of maternal primary caregivers, however this was rarely discussed. Nevertheless, this approach is limited in assessing whole family milieu and neglects the impact of other important relationships. Four articles discussed below explore the influence of other relatives, with three supporting the notion that they play an important role, and only one finding to the contrary.

Lee, Barrowclough, and Lobban (2014) found that service user views of positive affect from the whole family were significantly associated with relapse rates, whereas the same correlation was not found with views of only the key relative. This may reflect the influence of different relationships on well-being. This idea is supported in Subandi's (2011) discussion of one family where high EE was exhibited by one key relative, but not others living in the same household. In fact, it has been suggested that non-parental relationships are associated with increased warmth (Bentsen et al., 1998), although poor inter-rater reliability measuring the key construct of warmth limits confidence in this statement. Lebell et al. (1993) however, did not find any relationship between nature of kinship and service user outcome and as such, this hypothesis remains tentative.

3. What constitutes a positive environment?

Standardised assessments of familial environment have assumed that universal designations can be made to define broadly positive or negative family traits. What is less frequently discussed is how environments may be interpreted as positive or negative dependent upon personal, cultural and age-appropriate normative values.

Emotional “Over-Involvement”

This term is well-known in the EE literature (Amaresha & Venkatasubramanian, 2012), however traditionally it has rather negative connotations. Several articles in this review challenge this perspective as discussed in this chapter. As such, EOI is instead referred to as ‘affective involvement’.

O’Brien et al. (2006) and Schlosser et al. (2010) suggest that affective involvement can be positive and age-appropriate in adolescents and young adults. They found that moderate to high levels of emotional involvement combined with warmth, had a positive impact upon negative symptoms and social functioning at follow-up. As mentioned previously, these studies shared one third of participants and may therefore not represent truly different samples.

Consistent with this finding, Yu-Kit Sun and Cheung (1997) discuss how families with limited affective involvement performed more poorly on service user outcome and other measures of family functioning including provision of instrumental and affective needs. The authors of this study interpret affective involvement as interest and care over the individual.

Overall, perhaps affective involvement can exist at appropriate levels, which may differ for individuals and when combined with warmth serve to provide practical and/or emotional support for the individual.

Contrary to this hypothesis however, O'Brien et al. (2008) did not find associations between warmth, EOI and familial constructive behaviours. It is suggested that EOI at present is a multi-faceted construct which may benefit from further deconstruction to delineate subordinate components.

Cultural differences

Studies focusing on the effects of different cultures and ethnicities found interesting variation on the impact of what have been traditionally considered negative, high EE environments.

López et al. (2004) and Subandi (2011) used very different approaches but discussed how service users from different ethnic backgrounds may experience family relationships differently. López et al. (2004) re-analysed data from 40 Anglo-American (AA) and 35 Mexican American (MA) participants with schizophrenia, and their key relatives designated as exhibiting high or low EE according to the CFI. A significant association between family warmth and relapse risk factors was identified in participants from a MA background, but not in AA families. Family warmth was a significant correlate with a more positive outcome for service users from a MA descent, while critical environments were detrimental to AA but not MA participants.

Subandi (2011) used an ethnographic approach in a Javanese setting which did not attempt to report outcomes of family environments, however took an in-depth, qualitative approach. The LEE and participant perceptions of criticism, hostility and EOI identified three high EE families. They reported that although these traits are typically considered to have a negative

influence, in fact, the service user could interpret them in a positive way, as an expression of love. They discussed how criticism and warmth could co-exist within the same relationships, and reflected how this may be influenced by helpful cultural phenomenon, ‘Ngemong’, specific to this particular Indonesian philosophy. Although this study does not attempt to generalise findings beyond its scope, it does provide a rationale for the role of warmth and cultural influence as a critical mediating factor within otherwise putatively negative environments with participants from different backgrounds.

4. How can we recognise positive outcomes/environments?

Service user perceptions vs objective or key relative

In studying the effects of independent variables upon outcomes, researchers make assumptions about what it is possible to know and the ability of the measures available to identify it. When attempting to measure a concept such as family milieu, the validity of the assessment is affected by the informant. A crucial factor is this: who is the most appropriate respondent? When determining the quality of familial environment, six articles (Bentsen et al., 1998; Greenberg et al., 2006; López et al., 2004; O’Brien et al., 2006; M. J. Smith & Greenberg, 2008; Yu-Kit Sun & Cheung, 1997) assessed only the perspective of a key relative, whereas four (González-Pinto et al., 2011; Guada et al., 2012; Subandi, 2011; Tempier et al., 2013) asked only the service user. Four studies (Greenwald, 1990; Halford et al., 1999; O’Brien et al., 2008; Subandi, 2011) observed family interactions in efforts to assess inter-personal patterns more objectively, however under artificial conditions, with potentially different personal and cultural assumptions, it is not certain how valid this approach is. Studies assessing the perspective of more than one family member, particularly

when this included the service user benefitted from a more holistic picture of the milieu (Lebell et al., 1993; Lee et al., 2014; Schlosser et al., 2010; Weisman et al., 2005).

Interestingly, Weisman, Rosales, Kymalainen, and Armesto (2005) found no association between service user and key relative perceptions of family environment. Considering that Lee, Barrowclough, and Lobban, (2014) and Schlosser et al. (2010) both concluded that service user perspectives of family environments were more predictive than relative or objective measures, if this is understood to be so, then the results of studies that neglect patient perceptions could be under question. However, Lebell et al. (1993) reported that service users are very sensitive to their relatives feelings and attitudes towards them, so on balance, perhaps family member reports of family environment can give some worthy indication of the milieu.

Outcome measures – symptom remittance/psychosocial functioning

A striking difference between how the articles determined outcome measured was identified. While six prioritised symptom changes (González-Pinto et al., 2011; Lebell et al., 1993; Lee et al., 2014; López et al., 2004; Weisman et al., 2005; Yu-Kit Sun & Cheung, 1997), eight others also included more recovery-oriented measures such as quality of life and psychosocial functioning (Greenberg et al., 2006; Greenwald, 1990; Guada et al., 2012; Halford et al., 1999; O'Brien et al., 2006, 2008; Schlosser et al., 2010; Tempier et al., 2013). This may reflect the growing trend toward person-centred practice as recommended by NICE (2012) and meaningful outcomes for individuals endorsed by the National Institute for Mental Health in England (2005).

5. What factors can affect family functioning?

Given that family environment is known to impact the recovery of people with mental health issues (Amaresha & Venkatasubramanian, 2012), and that family interventions are considered effective treatment in reducing the rate of relapse (Pharoah et al., 2010), it would be clinically useful to have a clear idea of how these environments are affected. Seven studies discussed some aspect of this and are discussed in the themes that emerged.

Severity of Illness

Three studies discussed how the behaviour of the service user, or the severity of their illness had a significant impact upon the quality of relationships (Bentsen et al., 1998; Smith & Greenberg, 2008; Yu-Kit Sun & Cheung, 1997). Behaviours including amphetamine drug use and poor employment status (Bentsen et al., 1998) as well as a history of violence (Smith & Greenberg, 2008) were cited as damaging to familial relationships. It was not well distinguished whether the behaviours that families found more difficult to live with were in fact reflective of the severity of their loved one's illness, a factor that Yu-Kit Sun and Cheung (1997) found to affect family functioning, along with social support. These factors appear to point toward the higher impact of burden experienced as a result of the increased needs of the individual. Indeed, Bentsen et al.'s (1998) findings of improved warmth from non-parental relationships could reflect the lower intensity of involvement and as the authors propose, the knowledge that the caring individual has the freedom to leave which the parents may not. These inferences must be taken with caution however due to the small numbers of non-parental participants, a factor not unique to this study.

Family Climate

Three articles discussed how premorbid close and cohesive relationships could be conducive to improved family functioning (Smith & Greenberg, 2008; Weisman et al., 2005), however increased pressure and reduced resources such as financial issues and social support impacted family functioning and service user psychosocial functioning by proxy (Guada et al., 2012).

Negative appraisals

Two studies outlined how family responses to the individual's symptoms can contribute towards difficulty in relationships. O'Brien et al. (2006) reported that critical comments regarding negative symptoms made during the CFI task potentially reflects how they are not well understood as manifestations of illness, or perhaps as the more difficult aspect of illness to manage effectively. Smith and Greenberg (2008) discussed how poorer relationships existed where family members perceived that the service user had control over their behaviours.

Discussion

In the context of a literature base replete with the adverse effects of family environments on individual mental health, the aim of this review was to determine the potential benefits that could be gained from positive relationships. After selection criteria were applied, 17 articles consisting of eight cohort studies, six cross-sectional and two case-controlled studies were identified for review. Most studies used the CFI or CFI derived tools to measure home environments as part of quantitative methodology although one study used a qualitative, ethnographic approach. In general, the articles suggested that positive family environments can significantly influence individual mental well-being. This concept has been deconstructed to investigate environments more precisely and will be discussed in relation to existing psychological theory.

Findings in relation to EE

One of the more robust findings was in relation to warmth. Almost all studies that investigated this factor found parental warmth to be beneficial, usually in terms of reduced relapse rates for the service user. EOI was reconceived as 'affective involvement' due to findings that moderate to high amounts of EOI were actually associated with beneficial outcomes

. This is contrary to general perception in the current literature as EOI is usually framed in terms of high EE environments which are considered to be harmful. An interesting aspect of these findings is with the potential interaction of warmth and affective involvement and the different effects on people of different ages and cultures.

Some studies finding positive effects of increased affective involvement when combined with warmth suggested that high levels of involvement could be considered age-appropriate for adolescents (O'Brien et al., 2006; Schlosser et al., 2010). López et al. (2004) discussed how warmth was particularly important in the recovery of people from Mexican American families regardless of other high EE components, more so than those from Anglo American backgrounds. López et al. (2004) hypothesised that Mexican American families rely more upon a collectivist culture whereas Anglo-Americans place a higher value on individual autonomy; thus positive family environment may have a more substantial effect accordingly. Subandi (2011) then supported this hypothesis explaining that phenomenon reflecting established cultural norms could cause the individual to interpret criticism combined with warmth, as expressions of concern and love.

If there are age and culturally bound exceptions to EOI, the question is raised as to whether this typically negative construct is influenced by what is considered culturally appropriate. For adolescents, increased involvement when the individual is unwell could be considered appropriate and supportive where the typical developmental trajectory has been interrupted. Similarly, in other cultures, cultural norms may consider a higher level of support as ideal family involvement. Certainly affective involvement can be considered to exist on a spectrum where the poles (over involvement and disinterest) can present as damaging when outside of individually perceived cultural standards.

A systematic review focussing on cultural specificity of EOI discusses how the very construct of EE and its measurement are culturally bound (Singh et al., 2013). They too conclude that cultural values pre-determine normative levels of EOI, and found inconsistent data on the effect of EOI on individual outcomes.

In the present review increased contact with family members was also generally considered to have a positive influence on service user outcome, perhaps through provision of emotional support or simply as a by-product of a more general positive family environment.

Findings in relation to Attributions

A lack of research meant that conclusions regarding the influence of positive remarks and behaviours were difficult to reach. O'Brien et al. (2006, 2008) however, discussed how constructive attitudes may underlie the expression of positive remarks and behaviours which they found had a significant influence on beneficial outcomes. These factors may then impact upon the exhibition of positive family affect, a factor which several studies identified as correlating with positive outcomes (Greenberg et al., 2006; Halford et al., 1999; Lee et al., 2014). Unfortunately most studies did not investigate attitudes that may underlie positive affect, in fact, the only study to explore this did not find any reliable associations (López et al., 2004).

The assumption that positive intra-familial factors are underpinned by positive attributions is the central hypothesis of Attribution Theory (AT). Briefly, AT posits that relatives who consider the service user to be responsible for the difficulties associated with their illness tend to be more critical of them, perhaps in attempts to enforce behaviour change (Barrowclough & Hooley, 2003). Families with this pattern of attributions also tend to be classified as high EE. Low EE families on the other hand are assumed to be more likely to have a better understanding of symptoms being reflective of illness (Barrowclough & Hooley, 2003). While this is a potential explanation for the underlying mechanisms behind positive intra-familial interactions and individual outcomes, this review did not extend to adequately evaluate this hypothesis.

Findings in relation to Family Systems

Although the majority of research in this review focused only on one family member: the ‘key relative’, articles which explored family relationships further found that influences from other family members could be more important than solely key relatives in influencing individual outcome (Lee et al., 2014; Subandi, 2011). Only two studies investigated family cohesion which was consistently found to be advantageous to individual mental health as well as that of family members (González-Pinto et al., 2011; Weisman et al., 2005). Other factors which impacted family functioning were identified as: severity of illness, negative appraisals and quality of premorbid relationships. Furthermore, outside influences such as finance and social support were also identified as potential limiting factors.

The findings that the illness of one family member, influences other members of the family is consistent with family systems theory (Miklowitz, 2004). However this constitutes a relatively neglected area in the wider literature. Miklowitz’s article explains family systems theory as incorporating EE but fleshes out more positive aspects of family involvement and provides a more balanced view than the traditional EE construct. It seems likely that outcomes and family relationships are influenced in a multi-directional manner, however this was not well explored by the articles in this review.

As outlined in the introduction, many of these factors such as: severity of illness, social isolation and financial concerns have been previously identified as contributing to caregiver burden. High levels of burden suffocate the coping resources available to caregivers and their capacity to perceive positives.

Summary and reflection on quality issues

As Weisman et al. (2005) found no correlation between service user and key relative perceptions of family environment, and other studies (Lee et al., 2014; Schlosser et al., 2010) concluded that service user perceptions were most influential, this could lead us to question the validity of the findings of studies that only investigated the perceptions of key relatives. Furthermore, some outcome measures used may neglect the priorities of the participants and their families. Studies which valued recovery oriented outcomes as well as medically oriented outcome measures may therefore hold more functional value.

A difficulty with assigning patterns of behaviours to categories that were developed in western cultures, such as EOI, is that of assuming cross-cultural homogeneity. The factors believed to constitute EE have been called into question, perhaps due to the lack of adjustment according to cultural normative values because what is considered to be high EOI in one culture may not be perceived that way in another.

Perhaps due to space limitations, studies frequently neglected to detail the constructs they were investigating. At times it was unclear whether some phenomenon being investigated were substantially different from differently named concepts in other studies, for example warmth versus family positive affect; EOI versus affective involvement.

Clinical Implications

Early Intervention for Psychosis services guidance emphasise the provision of evidence-based interventions (NHS England, 2015). Whilst this publication references the NICE (2015) recommendations promoting CBT based interventions, other evidence-based approaches may well add to current psychosocial treatments.

That warmth, positive affect, and positive remarks can be supportive of recovery should be drawn from this review. Clinical interventions that aim to modify family interactions, such as family therapy, may benefit from emphasising the cultivation of warmth and positive relations within families as a central part of their approach. Given that warmth is a core component of compassion focused approaches (Gilbert, 2009), perhaps compassionate-mind based approaches could be incorporated into such family work. The solution-focused approach might also contribute to family interventions due to its focus on building on positive characteristics (De Shazer & Dolan, 2012). These findings are particularly relevant in light of NICE standards regarding the timely provision of family interventions (Department of Health, 2014; NHS England, 2015).

Harnessing interpersonal strengths within families may serve as a truly collaborative goal that can unite mental health services, the families, and individuals they serve. Organisational practices could refocus upon providing truly family centred support and mental health services could target staff training towards skills in building family strengths. This in turn may improve relationships between service users and mental health services. Changing the focus of intervention to a more positive, strengths based design may change the attitudes of staff and the general public regarding the culpability, or responsibility of the family and inform the discharge planning of those who have been admitted into inpatient settings. During times of crisis, service users and their families may benefit from respite, however when families are able to provide warm and supportive environments, the economic burden of service provision may also be alleviated.

Collaborative service design, improved attitudes and more appropriate environments combine to bring benefits to clients, over and above the immediate consequences of intervening to build family strengths.

Limitations of this review

This review would have benefitted from the inclusion of more than one qualitative article, given the narrow and specific cultural context in which the participants were embedded.

Furthermore, the databases used to conduct the search were confined to those holding clinically oriented publications. In line with the selection criteria and scope of the review the decision was made to focus on databases containing empirical literature. However it is acknowledged that a limited amount of peripheral or grey research may not have been identified.

A common limitation of the studies in this review is that of volunteer bias. Relatives who are sufficiently engaged in their loved one's care to participate in research are likely to have more supportive relationships than those the researchers could not access. As a result, analysis comparing 'good' and more difficult relationships, may in fact be investigating both relatively functional relationships. This limits the ability of research to identify potentially important factors distinguishing the two.

Attachment theory proposes that securely attached adults value close interpersonal relationships and are affect regulated, whereas ambivalent/resistant attachments are characterised by heightened affective expression which may include feelings of anger or anxiety. Given how these styles of relationships may play a role in positive or indeed critical or hostile interpersonal styles, it is perhaps surprising that more research has not discussed attachment style in this review. A recent systematic review by Gumley, Taylor, Schwannauer,

and MacBeth (2014) provides a good representation of current understanding about attachment styles and psychosis. Gumley et al. (2014) report that attachment avoidance relates to a perceived lack of parental care, while overprotection leads to preoccupation with relationships and discomfort with closeness. In light of this review's discussion regarding the variable impact of EOI research regarding the role of other attachment styles in mediating individual experiences of parental relationships may provide some insight. Further investigation of attachment styles and positive family environments may provide more theoretical understanding with which to guide research into positive familial influences on service user outcomes.

As discussed previously, many of the studies utilised the CFI or CFI derived measurement tools. This may constrain the ability of researchers to capture a comprehensive assessment of family relationships, due to the negative weighting of the tools.

Future research opportunities

There now exists the opportunity to develop our understanding of the multi-directional impact of interpersonal factors within the family system on individual outcomes and family functioning. Of particular interest would be the interactional qualities that can have a positive influence on individual and family outcomes. Further investigation could focus upon differentiation and/or interaction between some of the apparently overlapping constructs, or it could consider the underlying processes that make those factors important to the individual, as well as the necessary conditions within which those influences can make a positive impact. It might also be interesting to determine whether the distribution of burden differs among family members. Lee et al. (2014) and Subandi (2011) suggest that not only key relatives, but others within the family may moderate overall perceptions of family environment. Different

experiences of burden may explain how the key relatives' EE status does not necessarily relate to the remainder of the family. Magliano et al. (1999) discussed that key and other relatives do not differ in their experience of burden, however further investigation would provide a useful comparator to this individual, relatively small-scale study.

The literature base would also benefit from further investigation into the age-appropriate hypothesis and cultural variability of EOI. The development of adjusted categories in light of different cultural norms might represent a first step in cultural adaptation of this theory and aid the progression of future research.

Taking individual participant perspectives into consideration would benefit research into the impact of family relationships. Rather than assuming that EOI is intrusive and unwelcome, considering the normal level of EE for that particular culture as well as individual boundaries and perceptions will help us avoid making erroneous assumptions and contribute to our understanding of the EE concept.

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CHAPTER TWO

EXPLORING FAMILY EXPERIENCES AND RELATIONSHIP DYNAMICS WHERE ONE MEMBER EXPERIENCES PSYCHOSIS: “*WE’VE BEEN ON THAT JOURNEY TOGETHER*”.

Abstract

Background

Current research into families and psychosis concerns how adverse relationships impact symptomology. This research most commonly focuses on individual accounts and neglects siblings and service users. Therefore this study aimed to attain a comprehensive, more nuanced account of family experiences during an episode of psychosis, by recruiting several members of each family to capture a multiple perspective account.

Method

16 individuals from five families of adolescents experiencing a first episode of psychosis (FEP) were interviewed reflecting on their experiences of the family environment before, throughout and after the episode. Transcripts were analysed using Interpretative Phenomenological Analysis (IPA).

Findings

Three superordinate themes were developed which described methods of managing changes affected by psychosis: adapting through learning and communication; unity, sharing and delegating; and damage, repair and revisiting.

Conclusions/ Discussion

Families actively managed individual developmental and intra-familial relational difficulties by sensitively responding and adapting accordingly. The experience of this change was frequently stressful, however increased support was often appreciated by the service users as important and responsive to their needs.

Introduction

Rationale for research

For individuals experiencing psychosis, developmental milestones such as leaving the familial environment, living independently and beginning to form their own social circles, are frequently delayed or permanently disrupted (Harrop & Trower, 2001; Jungbauer, Stelling, Dietrich, & Angermeyer, 2004). With the closure of large psychiatric hospitals and the movement away from institutionalised care, the widespread discharge of patients towards a model of community care has resulted in families increasingly assuming responsibility of caring for and supporting the recovery of loved ones with severe mental illness (SMI).

The economic impact of psychosis is estimated at approximately £8.8 billion a year (Kirkbride et al., 2012) with lost employment and cost to services encompassing a substantial proportion of this figure. Furthermore, the economic value of unpaid carers has been estimated at £87 billion (Carers UK, 2012), equating to approximately 1.5 million carers in the UK (Arksey et al., 2002). Given the number of those experiencing mental health difficulties, their family members and the impact of caring and family support on mental well-being, it is of significant interest to economic and social well-being to effectively support this group.

Previous research & limitations

Saunders' (2003) review reported literature regarding coping strategies, caregiver burden, resiliency, depression, social support, behavioural difficulties, and family functioning as the primary focus and outcome of research. Family adjustment and adaptation were key constructs in crisis management. Where family relationships were discussed, it was regarding

how parental expressed emotion impacted upon the patient's symptomology, burden and mental well-being. Saunders noted that employment, finances, marital relationships and physical health permanently affected family identity, roles and relationships. Within the review, these latter issues were only briefly identified by a single article written over 20 years ago and again, do not reveal much about inter-relational dynamics.

There is a general deficit of whole family approaches in existing literature regarding psychosis. Where more than one relation type has been investigated, there has been a deficit in sibling and service user perspectives. The landscape of family dynamics has usually been described as an adjunct of a different research aim.

It has long been thought that family systems and environments, particularly high levels of expressed emotion (EE), have a significant impact over the course of an individual's mental health difficulties (Miklowitz, 2004).

As discussed in the previous chapter, EE is a concept used to describe the family environment, based on a structured interview with a key relative. High EE represents a toxic atmosphere, characterised by a high number of critical comments, hostility or emotional over-involvement (EOI). Conversely, warmth and positive comments describe a 'low EE' environment. A great deal of research has investigated the high EE concept and meta-analysis has supported it as a significant factor in the relapse of schizophrenia (Butzlaff & Hooley, 1998). More recent literature however has questioned the broad scope of EE. Research findings have been inconsistent and it has been suggested that the components 'criticism' and 'hostility' can be more specifically identified as risk factors, rather than EE more broadly (Alvarez-Jimenez et al., 2012).

Some drawbacks of EE research should be highlighted for example, the ‘gold standard’ measurement tool the Camberwell Family Interview (Amaresha & Venkatasubramanian, 2012), relies upon the report of only the key relative. Unfortunately this neglects the important perspective of the individual with the mental health difficulty who has a better understanding of the relational dynamic than the researcher. Also the perspective and influence of other family members is usually neglected. This could overlook important family dynamics which might compensate for, or counterbalance more difficult relationships. The validity of the contribution of EOI has also been questioned due to variable research outcomes hypothesised to result from varied developmental and cultural norms (O’Brien et al., 2006; Singh et al., 2013).

Finally, ‘warmth’ and ‘positive remarks’ are frequently neglected (Wearden, Tarrier, Barrowclough, Zastowny, & Rahill, 2000) and as a result, comparatively little is known about the influence of positive interactions. While there is a burgeoning literature base in how family support can positively contribute to service users’ recovery (Bird et al., 2010), measurement of contributions is often limited to medication compliance, relapse rates and hospital admission days. Nevertheless, evidence supports family therapy interventions in reducing hospital admissions and relapse rates (Barrowclough & Hooley, 2003; Bird et al., 2010) and is widely recommended in the treatment of those with schizophrenia (Department of Health, 2013, 2014). Research investigating familial impact upon service users’ health and wellbeing and vice versa in greater depth would broaden the scope of the evidence base.

Family therapy programs have been reported as consisting of psycho-education, problem solving skills and crisis management content (Bird et al., 2010; Pitschel-Walz, Leucht, Bäuml, Kissling, & Engel, 2001) with the aim to recruit several family members to treatment programs and support them in coping. This may function to alleviate burden and intra-familial attitudes (Berglund, Vahlne, & Edman, 2003). However, little is really known about the nature of whole family relationships when one member is experiencing mental health difficulties. There is opportunity for research to inform the development of targeted relational interventions.

The present research questions are posed in the context of literature that has investigated the phenomenon of carer burden (Awad & Voruganti, 2008; Knock, Kline, Schiffman, Maynard, & Reeves, 2011) and coping strategies of family members of people with SMI (Saunders, 2003). Unfortunately, existing research focuses on individual accounts, neglecting the impact upon other family members, perhaps under the mistaken assumption that burden is limited to key relatives (Magliano et al., 1999). Family systems are influenced by individual members in a reciprocal and dynamic manner (Cox & Paley, 1997), therefore it would be useful to analyse accounts of various individuals from within the same family.

The limited research which has delved into the relational dynamics within family systems has proposed that rigid interpersonal approaches (Miklowitz, 2004) such as feedback loops and self-regulatory processes, maintain patterns of relating (Minuchin, 1985; as cited in Saunders, 2003) in positive and negative ways. Additionally, secure relationships are described as supporting resiliency (Cicchetti & Lynch, 1993, p.97). Thus, complex family dynamics provide scope for intervention and so the concept merits further investigation.

In summary, research to date has focused upon practical coping strategies and carer burden. It has neglected family system perspectives, siblings, and service user viewpoints. This may be addressed by recruiting several members within the same family for research with a focus of what is meaningful within the family, and for the family. Investigating within each family system's unique context and processes will help us determine the impact this has upon family coping and ways of relating by involving both carers and the cared for from the same family. To understand intra-familial dynamics, this study will investigate not only difficulties and coping strategies, but also, changes in roles and relationships that may occur throughout the course of an individual's mental health difficulties. Recruiting families who have only recently experienced SMI, such as those with FEP may facilitate the discussion of changes that occurred as a result, as the change will be more recent and perhaps in the process of being adapted to.

Mental health services may benefit from further research to inform family directed interventions. Current interventions tend to have psycho-educational and/or cognitive behavioural underpinnings; a systemic perspective may provide more depth and understanding in the development of family approaches. This would enable services to meet the needs of families more effectively, and would support family and service user engagement and recovery.

Aims of this research

This research aimed to gain an understanding of family roles and relationships where one member has experienced a FEP. The primary research question was thus:

“How are relationships and roles within families experienced when one person experiences psychosis?”

A secondary research aim was to identify the adaptive, positive ways in which families adjust and cope.

Interpretative Phenomenological Analysis

Given the lack of previous research and the nature of the research question, further study would be most appropriately served by an exploratory investigation. The nature of this should be broad and open ended to elicit an unrestricted range of responses. A qualitative approach aims to provide scope for generation of data from the bottom-up (Willig, 2008) and would be most appropriate here.

Several approaches to qualitative analysis exist, however IPA (Smith, Flowers, & Larkin, 2009) was considered appropriate after the following considerations:

The epistemological position of IPA focuses more upon the individual’s interpretation or meaning of an event (or phenomenon) privileging their own perspective, rather than any attempt at an objective account of the event, or essence of an experience in of itself, in pre-conceived categories (Larkin & Thompson, 2012). Context was thought to be of particular importance here given the assumption that one’s experience of a phenomenon is embedded in their circumstances (Larkin & Thompson, 2012). Our understanding of this context should be emphasised to aid our own interpretations as an observing third party. IPA could be

considered to be compatible with a psychological perspective due to the value of the 'comprehensive unit' (Smith et al., 2009 p.2). This describes how an experience is connected with several levels in an individual's life, for example an isolated event may be interpreted in the context of wider meanings and values constructed as a result of one's past experiences. Related to this is the influence of the researcher and reader. A further strength of IPA lies in acknowledging the interpretative action imposed by the researcher (Smith, Flowers, & Larkin, 2009). This is essential in considering the differing perspectives of the participant and the researcher which in turn influences how the data is interpreted. This is in line with the aims of the research questions to understand meanings made by families from their own perspectives.

Method

Prior to conducting this research, full ethical approval was awarded by the National Research Ethics Service (NRES, see appendix B). The recruitment process described below ensured that informed consent was provided and allowed time for potential volunteers to consider taking part both before and after interview. The participants were aware of their right to withdraw at any point up to two weeks after the interview. Considerable care was taken to manage the intra-familial aspect of data collection and presentation, in order to minimise the risk of unwanted disclosures within participating families.

Context

Participants were drawn from an Early Intervention Service in the West Midlands, an outpatient specialist service for individuals between the ages of 14 and 35 experiencing a FEP.

Design

This study exclusively recruited three or more individuals from within the same family, including the service user. This novel design adopted a systemic approach, using multiple perspectives as a tool to understand intra-familial dynamics and meaning-making.

Data Collection

I recruited a convenience sample of participants who had expressed an interest in the project to their key workers. Key workers discussed the study and provided brief written information in the form of a leaflet (appendix C) and a more detailed information sheet (appendix D).

With permission, volunteers were then contacted by the researcher and interviewed after no

fewer than three days. Participants were encouraged to discuss any queries before giving written consent (appendix E) prior to interview. Verbal consent was sought again after a two week post interview reflection period. Participants were interviewed by myself, the researcher, in their home as was their preference. During the interview, participant distress was monitored and managed as necessary. In one interview the participant withdrew, before choosing to continue with the support of a relative.

Although my aim was to understand and consider whole families, participants were interviewed individually where possible, rather than in familial groups to allow them to speak freely, without censoring their perspectives.

I used an interview topic guide (appendix F) to begin and maintain the discussion, although it was stressed that this was purely a guide for conversation and I encouraged participants to express what they felt was relevant or important. I designed the topic guide in consultation with my supervisor and a parent of a service user who was not otherwise involved in the research. The explicit aim was to discuss the nature of family relationships and what, if any, changes had occurred since the onset of psychosis. Questions were open-ended and often circular, designed to encourage exploration of the family (e.g. what is their relationship like? How do you think they feel about that?). To socialise the participant into the slightly unusual nature of a research interview, I asked descriptive introductory questions (e.g. who is in your family?) as I anticipated that this would be a straightforward question to set the scene of the interview and begin discussion. Conversations may have deviated from the guide in both order and content as led by the participant.

Interviews lasted from 15 minutes to approximately one hour. They were audio recorded and later transcribed verbatim by myself for analysis. All participants were assigned pseudonyms. Other identifiable information was changed during the transcription process. IPA requires rich data pools that typically require interviews of approximately one hour to obtain, however participants who were relatively unwell were less verbose and so their interviews were substantially shorter. This should not preclude them from inclusion in the study as their perspectives are important, however it is acknowledged that the quality of data may be limited in certain cases. No participants chose to withdraw any part of their contribution after post-interview consent was sought.

Participants

A purposeful sampling approach was taken as per the phenomenological paradigm, to ensure a relatively homogenous group of people who have experienced the phenomenon under enquiry (Smith et al., 2009). Inclusion and exclusion criteria are detailed in table 5. below.

Table 5.

Participant recruitment inclusion and exclusion criteria

Inclusion Criteria	Exclusion Criteria
Families where one member has experienced psychosis	Children below the age of 16
All participants able to give informed consent to take part	Those who do not speak sufficient English to enable them to communicate sufficiently
At least three members of the family willing to take part	People without the capacity to give informed consent, for example those who are acutely unwell

My rationale for interviewing several members from the same family was to examine convergent or divergent themes, counterbalancing relationships and multiple perspectives upon the same phenomena. Given that previous family oriented research has tended to interview either relatives or service users, it was possible that dynamic issues within families have not been well documented.

Exclusion criteria were designed to ensure ethical practice and meaningful participation. One participant with non-fluent English speaking skills wanted to take part with facilitation from a relative. She considered herself to be competent in the English language, however was more confident to participate with support.

Table 6.

Summary of family interviewees

Family pseudonym	Family member	Relationship
Beech	Roger	Father/ Husband
	Sarah	Mother/ Wife
	Annabelle	Daughter/ Sister/ Service user
Birch	Caroline	Mother/ Wife
	John	Father/ Husband
	Ben	Son/ Brother
	Michael	Son/ Brother/ Service user
Linden	Manha	Mother/ Wife
	Rafee	Son/ Brother
	Safiya	Daughter/ Sister/ Service user
Rowan	Susan	Mother/ Wife
	Martin	Father/ Husband
	Jack	Son/ Brother/ Service user
Hawthorne	Denise	Mother/ Wife
	Robert	Father/ Husband
	Jo	Daughter/ Sister/ Service user

The total sample consisted of 16 individuals from five families; three families included both parents and the service user. The other two families interviewed consisted of one or both parents, the service user and a sibling. See table 6, above for an outline of the family members

interviewed, bearing in mind that other family members such as siblings and extended family may have existed but did not participate in the research. Participating families were ‘intact’ in that parents were together and offspring were either living in the home, or were in regular contact. No families reported significant financial hardship and all lived in stable accommodation. Demographic details of the participants are below.

Table 7.

Overview of participants’ demographic details.

Sex	Age range	Ethnicity	Occupation	Family member	Diagnosis
8 x Female	7 x 15-24	10 x White British	6 x Student	5 x Mother	4 x Unspecified Nonorganic Psychosis
8 x Male	6 x 45-54	2 x White Other	1 x Retired	4 x Father	1 x Paranoid Schizophrenia
	2 x 55-64	3 x British Pakistani	7 x Employed	2 x Brother	
	1 x 65+	1 x Black British	2 x unemployed or home- maker	5 x Service user/ offspring	

Families’ perspectives frequently varied regarding the service user’s psychiatric diagnosis. Some identified issues such as anxiety as being of primary concern. However, given the entry criteria for the study and the service, diagnostic information obtained from medical records was recorded here. Length of time within the service varied from six weeks to almost three years.

Data Analysis

Interview transcripts were explored using the IPA method of qualitative analysis as described in Smith et al. (2009). Initial readings of each transcript were accompanied by descriptive commentary and notation of linguistic material of interest (See appendix G for an example). Conceptual observations were also recorded as part of beginning to develop themes that arose. On an individual transcript level, clusters of conceptually similar annotations were gathered together to form themes, which were then grouped together, with supporting examples from the text. Individual participant's themes were then integrated with their family members themes where convergence or divergence and isolated constructs were observed. This process was facilitated by using note-cards to dynamically group and rearrange themes. Family level themes were collated into one document per family and further grouped with other families to develop superordinate themes (see appendix H). This process involved an iterative manner of movement between emerging themes and in-text detail to ensure faithful extraction of meaning so that the interpretation remained grounded in the data, as discussed in Smith et al. (2009).

As part of ensuring rigorous quality standards, credibility checking was carried out by using multiple analysts, a form of triangulation (Elliott et al., 1999). The research supervisor read portions of several transcripts and both interpretations were discussed. Evidence for emerging themes was then discussed, subjected to evaluation and consideration in relation to an overall developing narrative. I also kept a commentary of my ideas, questions and impressions throughout the analysis process. This kind of reflexive engagement with the data is discussed by Smith et al. (2009) as a core aspect of moving analysis away from descriptive towards

more conceptual and interpretative. I found this a very useful tool for noting commonalities across different participants, such as mothers, or service users.

These procedures of credibility checking, grounding in examples, coherence and owning one's perspective are all described by Elliott et al. (1999) as crucial aspects of maintaining high quality standards in qualitative research.

Normally within IPA research, fewer participants are recruited to facilitate in-depth analysis (Smith et al., 2009). However it was thought that a minimum sample of five families was required to provide sufficiently rich data at the inter-familial level. Given limited time and analyst resources, 10 individuals from three families were included in the IPA, while a further six individuals from the remaining two families were analysed via a more brief template analysis method (King, 2012). IPA and template analysis have previously been successfully integrated in this manner (Dennis, Larkin, & Derbyshire, 2013). Both IPA and template analysis share common epistemological grounding in phenomenology (King, 2012; Smith et al., 2009). The two methods can be combined effectively as IPA analyses data through bottom up identification of themes, while template analysis proceeds in a more top down methodology by fitting data to a developing structure. In this study a template of themes developed from the IPA stage was created with the main features resembling the themes summarised in table 8. The template was used to identify conceptually similar ideas in the remaining transcripts where convergent or divergent ideas could be examined, and new themes identified. In this way the template analysis functioned to ensure that the data was coherently and comprehensively analysed because themes from the initial IPA analysis were supported in new data and no new themes were identified. After this process, a complete summary of themes could be considered and superordinate themes adjusted or confirmed.

The Researcher

As IPA explicitly acknowledges the role of the researcher in co-creating and developing the analysis, I wish to discuss some aspect of my context which are sure to have influenced my interpretation of the data.

Having worked with individuals and carers in managing mental health difficulties including psychosis for some years, I have approached this research under the assumption that families are important and mutually influential. I had an awareness of existing research and the history of theory regarding 'dysfunctional' families and mental health difficulties. I therefore had a strong desire to gain a deep understanding of the varied perspectives and experiences within families of concern. Whilst I harboured suspicions that these interactions were potentially more complex than some research has depicted, I made attempts both individually and with my supervisor to 'bracket' off my own assumptions as part of a reflexive approach to promote bottom-up analysis (Ahern, 1999), and kept a reflective diary to facilitate this process.

Analysis

Participants shared ideas regarding adapting to changes that resulted from the psychosis, through learning and communication. They also described how different dynamics between individuals affected the family system and operated to sustain the family as a unit. The findings that emerged from the analysis are summarised in table 8. below, and the discussion that follows will examine the variety of meanings that constitute superordinate themes, with subthemes identified in **bold text**. Much consideration was devoted to maintaining participant confidentiality whilst exploring intra-familial themes and thus capitalising upon this unique characteristic of the study. Thematic convergence or divergence that emerged within families are highlighted throughout the analysis.

Table 8.
Summary of themes

Superordinate theme	Subtheme
Adapting through learning and communication	The benefit of social support Conflict between privacy and the benefit of sharing Learning increases understanding
Unity, sharing and delegating	The family is a unit Shared but delegated roles Special connections, secret languages Relationships strained/ tested but grown stronger
Damage, repair and revisit	Negative experience of FEP Damage to relationships, effort to repair Increased vulnerability and dependence prompts more intensive parenting and revisiting stages of development. How this was experienced

Adapting through learning and communicating

I derived this theme from harnessing a cluster of ideas expressed by families regarding learning of their loved one's difficulties for the first time and a process of coming to understand their experiences, how to support them and help them move forward. Individuals within families tended to take different roles in learning, with some actively researching, and others preferring to take a more passive approach.

All families described a period of realisation and adjustment to the new, unfamiliar behaviours and experiences they had experienced and witnessed. For many, this involved much learning about the experiences of their relative, the meaning of the diagnostic label, how to best respond to them and cope as an individual. The apparently obscure nature of the condition appeared difficult to understand and the concept of psychosis was extremely unfamiliar so most had a desire to know what their relative was experiencing on an intimate level. They found that **learning increases understanding** and so benefitted from educating themselves by attending classes, researching online, talking to mental health professionals and looking inside themselves, as mother Susan Rowan described: *"I thought I'd like to see what it's like.... I've sat there and tried to hear voices, I'll try anything!"*.

Another benefit of increasing one's knowledge as a result of understanding their experiences came from developing empathy, as well as reducing frustration. As husband and father Martin Rowan explained:

It also makes us understand what Jack's going through a bit more. [...] So that, that's been quite a big help to us I think. [...] It makes you more tolerant I think to the situation rather than kind of, to start with you're almost, I'd be banging my head

against the wall almost, in, in, in the sense that I couldn't get my head around why he was doing it.

Martin's quote exemplifies this family's perspective about learning and understanding, which was also shared by the other families. In this way, information and family therapy from EI services were frequently described as being helpful. Those who made efforts to improve their understanding described wanting to understand this unusual experience and help their relative through it, perhaps as a way of resolving their own anxiety about how to manage.

Others took a less active approach. For example Robert Hawthorne, father of Jo, was more cautious about information, actively avoiding it. He preferred to take a 'wait and see' approach, framing his daughter's experiences in the context of teenage hormonal changes. He expressed concern about being led by information in an unhelpful way:

I've borrowed Jo's iPad from time to time and her history shows that she's been looking up before, after she had come out with it but before she was diagnosed one way or the other and erm it was looking at psychosis and what the symptoms were. So I say "look don't put too much into your mind because erm you can self-diagnosis wrong too much" you know. And I'm not convinced yet that it is anything to do with psychosis.

Robert's scepticism about his daughter's diagnosis and his previously expressed perception of psychosis as a "big word" may illustrate how anxiety perhaps borne out of a lack of knowledge, or simply the potentially serious implications of such a diagnosis, may result in

some avoidance. As his daughter and his wife were far more active in their efforts to discover and learn, it makes me question whether his contrasting approach allowed him to maintain some balance or sense of normality in the family, moderating the emotional tone.

There was a general sense that families appreciated the value of learning as it was perceived to facilitate understanding, empathy and thus communication. However there also appeared to be a **conflict between the value of privacy and the benefit of communication/ sharing**. Families recognised that poor communication, in the form of not talking, or arguing, could be a symptom of illness and did not benefit anyone in the family as difficulties remained unspoken, leaving problems to grow. As sibling Ben Birch described:

It used to be we'd just keep it to ourself and stuff, and like, that'd mean the problems would get worse. We'd be in a mood and be like, "Oh what's wrong?" "Nothing, nothing is wrong" and then, but really something was wrong but we wouldn't be talking.

Here Ben summarises an experience that was shared amongst his family and was common across most families, where limited communication isolated individuals within the family and perpetuated personal as well as relational difficulties. On the contrary, clear and frequent communication was valued by families as it enabled relatives to work together towards resolutions, bringing more closeness, a sense of unity and supportive atmosphere, as he continued: *"the ups are also that he can vent it because that means that he's not keeping it to himself, he sort of, we're, like, we can help each other feel better by talking to each other."*

In the Birch family's case, improved communication was an explicitly stated result of Behavioural Family Therapy, as provided by their local Early Intervention in Psychosis service. This was expressed by each member of Ben's family. Not all families had received this therapy, but all described benefits from shared communication.

The issue of privacy arose because fear of stigma was a primary concern. Only some families shared their experiences beyond the nuclear family and rarely were personal issues discussed with non-relatives. This may have been a reflection of a stereotypically British culture, as John Birch, father and husband within the family explained:

Society just expects you to plod on, carry on as normal, stiff upper lip, er, chin up, don't worry about anything. Be robust, be really tough, don't succumb to all this stress it's, 'cos it's just not very British. I think society expects you to be able to cope with that and I don't think... I don't think I can very easily.

As John explains how a stereotypically British approach does not promote sharing one's hardships, he later describes benefitting from learning that others too, experience difficult times. This attitude was divided between the families.

Some participants discussed the benefits of sharing more openly in terms of reducing stigma, helping those who may also be experiencing mental health difficulties and increasing understanding towards themselves or their relatives. In fact, John's own son who experienced a FEP deliberated the pros and cons of protecting himself from stigma, versus potentially helping others who themselves might experience difficulties. Whilst John's family preferred to maintain privacy, some others were more open within wider family or with friends.

When invited to reflect, many families expressed gratitude for their family and their circumstances compared to others in a worse position. As a result of attending a carer's group, Martin Rowan described **the benefit of social support** in learning from others and gaining a sense of perspective into his own family's experiences:

“We're both going to a care group as well which helps to, helps carers to kind of understand what the child is going through and that's been very good because that's given us a lot more insight into the level that we're at and the level that other people are at because everyone is at different stages, so we realised that, we're not at the end but we're in the middle, you've got other people that are just coming into it and, you know you start to kind of then think “well hang on a minute we're, we're not that bad, it's not that bad for us, there's people worse off than us”.

Martin reflects a common theme shared across all families that where social support was available, it was informative and valued. Support from various sources within the community - for example carers' groups, churches, mental health services or friends – were also cited as being important in helping parents in particular, cope. As mother and wife Sarah Beech commented:

“I do feel that I'm fairly well supported and definitely by the, you know, the early intervention team and just knowing that, if I need to I can call someone. I don't think I've had to, maybe I did once or twice at the very beginning but, knowing there is someone there to, that I can call if I need to if there's a crisis with [daughter] is a big

help, you know just knowing it's there, because otherwise it can, it feels quite, it is quite isolating"

This quote highlights the benefit of specialist mental health services, whose intervention may not necessarily have been intensive, but provided a sense of support which helped families to manage and reduced the risk of isolation. All families expressed appreciation for the availability and support of this specialist mental health service. Perhaps these subthemes illustrate how a culture of not discussing mental health difficulties risks leaving families feeling lost and unsupported. Families appeared to feel conflicted between wanting to protect oneself or one's relative from stigma, whilst simultaneously wanting to help others and appreciating the benefit from hearing other's experiences.

To summarise this theme, participants essentially demonstrated coping styles which prompted them either to investigate more, or to avoid direct engagement with learning; a finding which will be considered later. I thought that perhaps this reflects the delegated roles strategy discussed in the next theme, where overarching family goals are achieved through strategic use of individuals who may represent or become local 'experts'.

Unity, sharing and delegating

This superordinate theme was developed to encapsulate the feeling of the family being a unit, functioning with a shared goal in mind and delegating tasks according to ability. Generally, this was limited to the nuclear family, but two families were sufficiently close with extended family to include them in their idea of **the family as a unit**. As such, the well-being of the group, is dependent upon the well-being of individuals, as John Birch explained: "*these*

things wax and wane. Any, any sort of dip affects us all.” Therefore, the impact of the FEP rippled throughout the unit and so the needs of more than solely the service users needed to be addressed, as he continued: *“mental health is four times more expensive in this house because there’s four people to look after rather than just one”*. This was reflected amongst the Birch family, and also among other families.

While the experience of the FEP was universally depicted as difficult, families described how **relationships had been strained but grown stronger**. Perhaps that shared impact and shared purpose of recovery united the family further and contributed toward the development of even closer relationships, as Martin Rowan described: *“everyone’s been drawn into the fact that we have to kind of look after each other, we have to look after Jack. So in some senses I think it’ll probably make us stronger.”*, an idea reflected with his wife, and shared amongst other families. Furthermore, experiencing difficulty together appeared to provide depth and shared understandings:

“...obviously we’ve been facing it together and discussing it and, and praying about it and all that, and so I think, yes it’s, it, it’s been much the same, perhaps strengthening and deepenings as well...”

Here Roger Beech (father and husband) seems to outline how good relationships have been reaffirmed through shared experience where mutual support and open communication had been a key feature.

Shared goals such as specific events or overarching family cohesion were reached through having **shared but delegated roles** and tasks. Roles such as ‘organiser’, ‘arranger’,

‘confidant’ or ‘counsellor’ were flexibly delegated according to character, age-appropriate or time availability related abilities. With this new experience, it seemed to me that those with more understanding of mental health issues or services were considered the local ‘expert’ and relied upon accordingly, as John Birch explained: *“I’m no expert but I’m quite happy to be considered the expert because it helps people have a central point to talk to, whether I am is [laughs] you know, debatable.”*. Here this family, in common with some others, appears to organise itself around the allocation of a role that provides a framework for discussing specific issues. This role may have been assumed through personal or professional experience, or through initiation of an active role for example through conducting independent research, or volunteering to help.

It was most common for especially close relationship pairings to emerge as being helpful to all individuals within the family. These **special connections and secret languages** largely revealed ways of being with one another where secrets could be shared and a close bond fostered. Interestingly, although the concept of the special connection was a theme that ran through each family and many of the participants’ accounts, the forms which these connections could take were diverse and varied. A comprehensive list of different kinds of special connection is provided in table 9 to illustrate the range of connections. In the example below Michael Birch, an offspring and sibling who has experienced psychosis, describes reciprocal behaviours to enjoy shared pleasures that operate to create a unique, secret bond between himself and his brother:

“We always do things like that and I like that, it’s nice and we get each other like little presents and like that, we’ll do that with my parents but [whispers] they don’t

always like us eating sweets and stuff so... it's kind of a little, secret brotherly thing that they don't know about [laughs]"

This bond is distinct within the family, was reflected in his brother Ben's testimony and was also recognised by their parents as a special relationship. This special relationship is where they can enjoy private activities without judgement or disapproval. It was a common theme among the families that special bonds developed through sharing interests and private things. Factors facilitating special connections included similarities in age or gender and time spent together, appearing to contribute towards a shared understanding exemplified in this quote from Michael: "*we just, we get each other and it's good.*" See table 9 for instances of this subtheme.

Table 9.

Minor themes within special connections

Sub theme	Instances	Participant
Special Connections	Advice	Michael, Ben, Annabelle
	Confidential	Michael, Ben, Rafee, Jo
	Shared interests	Michael, Ben, Jo, Caroline, John, Manha, Robert
	Relatable	Michael, Ben, Robert
	Secret brotherly things	Michael, Ben
	Openness	Michael, Ben, Jo, Roger, Denise, Robert
	Reciprocal helping	Michael, Ben, Safiya, Manha, Sarah, John, Martin, Manha
	Time together	Michael, Ben, Jo, Caroline, John
	Relaxed, no pressure	Michael, Ben, Caroline, John, Jo, Denise
	Mutual understanding	Michael, Rafee, Jo
	Age similarity	Michael, Ben, John
	Bonding experiences	Michael, Ben
	Being there for each other/ Availability	Michael, Ben, Manha, Jo, Denise, Roger, Sarah, Annabelle, John, Robert
	Knowing each other well	Michael, Ben, Jo, Roger, Sarah, Robert
	Same sex	Ben, Rafee, Jo, Roger, Robert
	Support	Safiya, Manha, Jo, Roger, Sarah, Annabelle, John, Martin, Susan, Rafee, Safiya, Robert, Ben, Michael
	Sharing things	Safiya, Sarah, John, Manha,
	Similar character	Roger
	United	Roger, Sarah

Although not all relationships within the family were perceived to have the same quality as the ‘special connection’, ways of relating were developed, often through a shared interest, as Sarah Beech described:

“Sport is their language so they’ll have those conversations and, [...] they just enjoy sport and they like talking about it and so I think as probably, as [son] has got older they’ve grown closer and in that way, finding sort of [laughs] finding a language. [...] so it’s a different kind of closeness, I guess that’s what I’m saying..... [son] is much more of an introvert, more like me but, so perhaps that’s why I notice the sporting language that they share [laughs]”.

In this excerpt, the topic of sport provides a platform upon which a parent and child can spend time together, developing a relationship upon a shared interest. In this way, most if not all family members shared a unique connection with each other that was reasonably exclusive to them and facilitated conversations and time together. A particular quality important across participants was that of availability. Spending time with one another appeared to be a cornerstone from which close relationships were built. Perhaps where individuals did not have similar characters, finding a common interest provided a language to connect with and facilitated spending quality time together.

Ultimately the families considered themselves to be a cohesive unit, and shared goals appeared to be organised within the group. Within this system exist special connections and secret languages. Secret languages seem to facilitate relationships. I wondered whether special relationships provided a sort of relief from more demanding relationships, enabling

individuals to perform reciprocal helping roles and bonding experiences, whilst feeling relaxed to be themselves without pressure and with feeling accepted. This is an idea which merits some engagement with theoretical frameworks. Certainly I noticed active efforts to repair difficulties which I discuss in the next theme.

Damage, repair and revisit

A **negative experience of the FEP** was reflected across all of the families, as Susan Rowan expressed in the strongest terms: *“It was horrendous. Absolutely horrendous....I wouldn’t wish it upon anybody. Horrendous”*. This experience was perhaps made more difficult by the apparently sudden onset or discovery of illness, as service user Annabelle Beech described: *“I would say they were kind of shocked because they didn’t expect it at all when I got first ill”*.

In fact, the sudden onset and destructive experience of the illness was shared by several families who often used powerful language to reinforce their experience:

“basically it all kicked off when when Sarah was was helping her erm, change her, her er um, er, erm, sheets on her bed one day and lifted up the pillow and there was the kitchen knife and boom”

Here Roger Beech uses violent language and likens the discovery of his daughter’s paranoia to an explosion. His wife Sarah similarly uses this metaphor in her description of the discovery: *“...because it was so... sudden, seemingly and out of the blue and unexpected um and even... quite um mind blowing”*. The couple’s experience of this event has therefore been described as unexpected and destructive. This is reinforced by another parent,

John Birch: "...we've just contained it. Our fallout zone if you like". Here he too uses the metaphor of a bomb explosion that the immediate family have made efforts to contain so that it does not infect, or damage others. These metaphors really convey a sense of how damaging and life changing this event was experienced.

The negative experience was accompanied by feelings of blame and shame within the families, to varying intensities. From the relatively benign feelings of irritation expressed by mother Manha Linden: "*I dunno what's wrong with Safiya. She's talking like that you know and she annoying to everyones*" to more extreme expressions of strain felt by the family:

"I think he's pushed the family to the limit in the sense that erm erm it's put us under a lot of pressure and a lot of strain and a lot of worry. ... Erm and I think that the biggest thing that we found was that, with the situation he got into, it's all the lying and the deceiving... so yeah that's erm that's been a hard thing to deal with."

Here Martin Rowan blames his son for some of the difficulties and emphasises the detrimental relational aspect of violated trust. Perhaps this variation reflects each family's values or indeed, the severity or stage of illness of the service user, as Martin Rowan's son, Jack was currently experiencing more symptomology than other participants. Despite this, Jack expressed sensitivity to these feelings and expressed it as an almost tangible presence in his home environment:

"I: And why do you think people argue less now?"

R: Because I'm causing less stress...because it's my fault, you know, I was the one messing around...I feel like the past is like haunting the house."

Here Jack describes his responsibility for the strain on the family and a sense of shame that is prominent in his mind, darkening the atmosphere. In this way we can see that all members of the family felt a substantial and jarring negative effect of the onset of psychosis and relational difficulties which followed.

Perhaps as a result of stress brought on by the FEP, conflict or difficult relationships sometimes emerged. Interestingly however, where there was **damage to relationships**, **efforts to repair** were made. For example, other members of the family took active roles in counterbalancing, or repairing fractious interactions as John Birch noted:

"We could almost be a good cop bad cop setup, [...] often if Caroline's having a rant or a moan about something with Michael or Ben I tend to let them take the other op, the other point of view, not to be contrary to Caroline but to try and "look you know, actually, this is, this is tough love and I'm just trying to show the love bit"

Not all families talked about experiencing particularly difficult relationships, however in those that did, this quote exemplifies a theme shared across most, that difficulties were noticed and acted upon. Furthermore, John's son, Michael who had experienced a FEP, revealed that he noticed this action, and other families reflected this pattern. In this way, efforts were made to relieve the individual of stress and go some way towards alleviating what could become a negative environment. Furthermore, some took the role of protecting the

service user by defending their behaviours and helping others to understand their difficulties and adjust expectations accordingly.

It may be that experience of a FEP reveals an **increased vulnerability** in the individual that prompts relatives to respond with more active or **intensive parenting** as required. The majority of participants described their loved one as having become more **dependent** upon them, causing them to **revisit stages of development** that were reminiscent of earlier childhood. *“we first went to the doctors when he was 14 and he sat on my husband’s knee and I read out all the things that Jack was doing and he became like a little baby again, you know.”* Here Susan Rowan describes this sense of vulnerability in her son, illustrating the increased reliance on his parents. For some families, this felt like a natural behaviour, but for others it could be frustrating or uncomfortable and difficult to manage appropriately, for example:

“Because we know about his past and we get all worried like, if he’s upset we wanna make sure he’s okay. But at the same time we don’t wanna keep going “Are you ok?” because then he, he’ll say “Oh don’t patronise me” or whatever. So, we have to be careful”

Here Ben Birch illustrates firstly, how even younger siblings can be recruited into a more parental role and secondly, how difficult it can be to strike the right balance between caring, and being perceived as over-involved or annoying. **How this was experienced** by the service user, seemed to depend upon the level of understanding an individual had into their needs and the intentions of their relatives. While Ben highlights how this increased type of parental role

can be experienced as annoying, it was also expressed by several service users as reassuring and helpful; indeed, a son sitting on his father's knee as Susan Rowan described appears to be an active attempt to elicit such care. However, even this dynamic is susceptible to change, perhaps to reflect changes in well-being, as Susan continued: *"I think I get on his nerves because I'm too close and he wants to grow up."* In those who did experience increased parenting-type care as annoying, they acknowledged that in hindsight, if not at the time, this was appropriate and even necessary as Susan's son Jack, who experienced psychosis, said: *"It's more like constantly asking me how I'm feeling and stuff.... when things were at their worst. I: And how do you feel about that? R: Fine it needs to be done"*. There seems to be a complex quality to this interaction. It makes me wonder whether there is a dance between them, where the parent (or sibling) needs to be sensitive to the wants and needs of their child (or sibling), and able to meet those needs, perhaps in ways that respect their developmental stage.

Upon reflection, I see this theme as encapsulating features of the family system that work to balance or maintain relationships and progress toward family goals. Where strain begins to damage, others can take or revisit roles which can relieve and potentially restore relations. Resulting from this, there are implications upon the way existing literature is interpreted which should be explored further.

Discussion

The aim of this study was to gain an understanding about how family systems operate during a FEP. The superordinate themes describe how the family system reacts, adapts and finds a way of moving forward with the disruption that FEP can bring.

The theme **adapting through learning and communication**, describes how individuals within the system may take an active role in discovering information about their loved one's experience, and how to cope. Alternatively, some relatives took a more passive approach and were more keen to frame experiences within a more familiar framework. Whilst there was some conflict about the extent to which one should share information, given the cultural climate, it was generally understood that benefit came from frequent and effective communication.

Unity, sharing and delegating discussed how the family felt strained, but drawn together in a unified stance in the face of illness, and a strategy of sharing out responsibilities. Within this theme, special connections appeared as a reflection of unique bonds within the group, and ways for less well connected relationships to develop.

Finally, the theme of **damage, repair and revisit** described how potential relational difficulties were noticed and efforts made to repair. Meanwhile, earlier stages of parenting were revisited as the service user required more intensive support, and how this was experienced varied perhaps dependent upon the well-being of the individual.

These common experiences were reflected across all families, despite the variation in stage of illness that existed between them. Some service users were having more difficulties experiencing symptoms of psychosis than others who were perhaps farther through their

journey of recovery. Families' intensity of support also varied substantially as a result of their loved one's stage of recovery.

In light of the substantial evidence base for the efficacy of psycho-education as part of family interventions for schizophrenia (Pharoah et al., 2010), it is unsurprising that families reported a benefit from communication and learning. Participants described that better understanding increased their ability to empathise and be more tolerant. Barrowclough and Hooley (2003) characterise low EE partially as reflecting sound understandings of the individuals' difficulties and symptoms, so this study may lend some support to Pharoah et al.'s (2010) suggestion that this benefit results from a reduction in EE. Additionally, these findings reinforce the underpinning philosophy behind the Open Dialogue approach where the primary aim is to generate dialogue within families, social systems and professional services (Seikkula et al., 2006). It is also unsurprising that stigma arose as an issue that made it more difficult to access social support as there is still much work to be done in de-stigmatising mental illness. Comparatively limited research regarding family experiences of stigma exists compared to that of the individual (see Corrigan & Miller, 2004 for a review). As Knight, Wykes, and Hayward (2003) discussed; self-stigma can significantly diminish self-efficacy as the individual experiences difficulty in retaining a positive perspective of themselves and so they require much support in maintaining a focus upon recovery. As Knight et al. (2003) noted that stigma was experienced from family members as well as outside the family, it would be interesting to further consider the influence of family members on self-stigma, and the impact of stigma on family coping.

Although the experience of a FEP was generally regarded as very difficult, it was remarkable how some families described having been drawn closer together, becoming more unified as a result. Facing challenges together, adapting positively and growing in some way reminds me of resilience, a rather nascent concept in mental health literature. Resilience has been described as “The successful coping of families during life transitions, stress, or adversity” (Black & Lobo, 2008, p.33) and has been identified as a possible factor in the family’s experience of mental health difficulties (Marsh et al., 1996). Perhaps this study has illustrated that these families showed resilience at this time. Conceivably, this study represents an account of resilient families, and factors involved in this were highlighted in the surrounding themes for example learning and communicating, sharing and delegating, and repairing and revisiting. These factors represent flexible and adaptive responses to challenges, sharing many of the characteristics of resilient families described by Black and Lobo (2008) such as family member accord (coherence, nurturance...), flexibility, communication, etc. It is possible that the families in this study were able to be more resilient due to the relatively short duration of illness experienced by their loved one. The sample of participants were unusual in that they were adolescents, so their journey of psychosis had been relatively short and in some cases quite mild. Perhaps longer illness increases perceived burden, eroding the family’s ability to cope and reducing their resilience. Furthermore families expressed satisfaction with support from professional services as they received specialist care, with little delay. Perhaps they were able to be more resilient because their burden was relatively light, although studies regarding caregivers of children and adolescents with schizophrenia have suggested that their burden is in fact greater than for those who provide care for adults (Knock et al., 2011). This idea that families felt that they had grown in some way suggests that there may be a useful analogy to be drawn with the growth that can occur at an individual level after traumatic stress (Joseph &

Linley, 2006). However, typically trauma has been situated at the individual level following life threatening events, therefore may require some caution in applying this understanding to families experiencing this kind of stress and strain.

Minor themes within ‘special connections’ were profoundly reminiscent of how highly valued small, thoughtful gestures are and their association with silent connections in close relationships as discussed by (Gabb, Klett-Davies, Fink, & Thomae, 2013). I might suggest that this research therefore broadens the scope of their findings beyond romantic relationships. The emergence of special connections within families presented an interesting question regarding what impact this might have on individual resilience, or overall family cohesion. The fact that the majority of participants spoke of a special relationship and described benefitting from it prompted me to consider how it might help them. Research has identified social support as an important protective factor for individuals and their families (Saunders, 2003) as isolation is a common problem. As such, interventions targeting social isolation have demonstrated good clinical outcomes (Saunders, 2003). However, this appears to refer to less personal relationships so may not extend to especially close connections.

Social support has been discussed as important to individual and family resilience (Black & Lobo, 2008; Southwick, Vythilingam, & Charney, 2005), and in turn resilience has been supposed to enable the individual to protect themselves from criticism or over-involvement (Miklowitz, 2004), so perhaps these special relationships help counterbalance, or alleviate, more difficult relationships. Some of the factors (such as availability, reciprocity etc.) underpinning these special relationships are reminiscent of core values in secure attachment patterns (Ainsworth, Blehar, Waters, & Wall, 1978; Danquah & Berry, 2014). This leads me

to consider the active behaviours described in the theme: damage, repair and revisit.

Sensitivity to ruptures, care seeking behaviours and the ability to respond appropriately all reflect qualities described as essential in secure attachments (Ainsworth et al., 1978; Marvin, Cooper, Hoffman, & Powell, 2002).

Attachment theory describes the development of our first relational bonds with primary caregivers that operate to elicit care (Bowlby, 1969). Many participants described care seeking behaviours reminiscent of patterns described in the attachment literature (Bowlby, 1969), consistent with the assertion that the attachment system is stimulated by threatening events such as illness (Bowlby, 1969; Gumley et al., 2014). If this is considered together with literature questioning the inappropriateness of emotional ‘over-involvement’, I might suggest that where more intensive care is elicited, it is in fact appropriate. However, this does require a fine balance on behalf of the caregiver to demonstrate qualities such as availability and sensitive responsiveness to recognise care-seeking and exploration-seeking behaviours (Ainsworth et al., 1978). Perhaps it is where care is not sensitively responsive that a mismatch between desired and received level of care occurs and difficulties arise.

Methodological Considerations

This study used IPA with the aim of gaining a detailed insight into roles and relationship dynamics within families where one individual is experiencing a FEP. A strength of the design was the multiple perspective approach, enabling a 360 degree panorama of the family environment embedded in its context. This was also one of relatively few studies to include siblings in the design, despite their significant role.

It must be acknowledged that template analysis is a less sensitive analytic tool than IPA, however in this context it had the benefit of allowing the meaningful inclusion of a larger sample of data than would otherwise have been possible. Furthermore, it benefitted the study to extend and validate the initial analysis through a secondary data set. Template analysis could be criticised for imposing themes upon the data, however in this case it was felt that this risk was minimised through the use of IPA initially for the majority of the data and then to create the template.

This design lends itself to multiple levels of analysis. This analysis was written with the intention to give an account of the different levels within the data. Had this been a PhD assignment, or several articles, it would have been possible to devote larger chapters to each different level, such as sibling relationships, marital relationships, experience of mothers, service users, etc.

Consistent with the IPA approach, the results of the study are limited to the interpretation by the researcher, of a small homogenous sample. This does limit the generalizability of the findings. It may be that this sample were illustrative of high functioning families with adaptive coping strategies who as a result, were well engaged with mental health services and thus willing to participate in this research. Therefore, this study was not able to investigate the entire range of possible experiences of families experiencing FEP, but it does bring a useful perspective on what 'good' can look like. Similarly, a prerequisite of capacity to give informed consent in order to participate in the study meant that service users represented a sample of individuals who were relatively farther along their path to recovery. Therefore, this study may have been unable to identify aspects of relationships which could have been

affected by more severe symptomology. This analysis uses quotes from a range of participants, however a few voices have been heard marginally more frequently than others. While all themes were supported by many participants, it was the case that some spoke more eloquently, or more succinctly and therefore made more illustrative contributions to the themes. Smith (2011) supports the ability of especially salient quotes in illuminating qualitative research in the context of contributions from other participants.

While the participants did have varying diagnoses and comorbid issues, this is reflective of the wider population within Early Intervention Services. It is in fact highlighted in NHS England, (2015) service standards which highlight that diagnostic uncertainty should not be a limiting factor in providing intervention and emphasise rapid access.

Given the differing lengths of time participants were involved with the service (from six weeks to three years), it was inevitable that families had received different interventions. This may have altered their family dynamics and also perhaps their ability to discuss them. This may have benefitted the study as participants may have been more reflective of their interpersonal patterns, but it may also have introduced heterogeneity into the sample. This was not thought to detrimentally impact the data collected in this study given that again, this is likely to be representative of the wider population and the aim of this study was not to examine experiences of mental health services, but family experiences of psychosis.

Recommendations for future research

While there is a burgeoning interest regarding attachment and mental health (Danquah & Berry, 2014), perhaps future research could investigate the impact of illness on attachment seeking behaviours and the experience of this between family members, especially where the

service user is an adolescent or adult where more independence was previously the common expectation. In light of some tentative research questioning the influence of EOI (O'Brien et al., 2006; Singh et al., 2013), perhaps this construct could be further considered bearing in mind my hypothesis regarding its relationship to attachment seeking behaviours and sensitive responsiveness, particularly in adolescent age groups.

It was curious to discover the role of individuals within the family in managing a difficult relationship. Further research could aim to build a more comprehensive account of disruption management techniques and further investigation into which members of the family take what active roles, or whether this is confined to parents.

Recommendations for clinical practice

While communication and family problem solving are frequently targeted in clinical interventions, perhaps more delicate relational interactions could also be built upon considering information how other family members can support and counterbalance interpersonal difficulties. Further, where interpersonal difficulties arise, perhaps methods for developing close relationships described by the participants, such as with secret languages, could be utilised to help find a common ground to facilitate time together and foster more positive relationships as a result.

Finally my hypotheses about the role of emergent themes potentially involved in building resilience, in conjunction with factors discussed in other literature (see Black & Lobo, 2008 for a conceptual review) could be incorporated into existing family interventions to promote developing robustness and protect against burden.

These suggestions may enable practitioners to provide a more broad approach to family interventions, however should be well within the scope of existing provision.

Conclusions

While the experience of the onset of a FEP was widely regarded as an extremely difficult time, it should be noted that families made active attempts to understand and make sense of it.

While the families experienced significant strain, efforts were made to repair interpersonal difficulties, while sharing responsibilities and working together towards a common goal which was recognised as having brought them closer.

Of particular interest was how attachment seeking behaviours were observed and considered to be out of sync with the service users premorbid developmental stage. This study therefore highlights the value of an attachment-oriented approach in guiding clinicians and family members' interactions with service users. Future research could focus on illuminating the effect of mental health crisis on attachment seeking behaviours and the impact of this upon the family system.

Another novel finding within this study was how families described special connections and secret languages operating to facilitate close relationships, thus supporting the participants and potentially counterbalancing more difficult relationships. This benefitted individuals and families as a whole. I would therefore encourage clinical services to promote interventions designed to support the fostering of such relationships, perhaps inspired by the collection of instances illustrated previously in table 9.

These findings are considered novel in light of a literature base that scarcely investigates more positive relationship dynamics that can occur during this time and could serve to improve collaboration between mental health services, service users and family carers.

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CHAPTER THREE
PUBLIC DOMAIN BRIEFING DOCUMENT

This document provides an overview of the thesis submitted in partial fulfilment of the requirements for the degree of Doctorate of Clinical Psychology (Clin.Psy.D.) at the University of Birmingham. This document summarises a literature review and an empirical paper both written in preparation for submission to peer-reviewed journals.

LITERATURE REVIEW: HOW DO POSITIVE FAMILY RELATIONSHIPS INFLUENCE
INDIVIDUALS WITH PSYCHOSIS? A SYSTEMATIC REVIEW.

Background

Evidence suggests that stress and a difficult family environment can overwhelm people who are already vulnerable to psychological difficulty. This can result in mental health problems including psychosis, where people might hear voices or experience paranoia (Amaresha & Venkatasubramanian, 2012; Lardinois et al., 2011; Myin-Germeys & van Os, 2007; Phillips et al., 2006; Zubin & Spring, 1977). Families can also help one another moderate experiences of stressors (Harrop & Trower, 2001) and although burden can make it difficult for families to cope some do experience personal growth and resilience (Marsh et al., 1996; Saunders, 2003). Most current research focuses more on the negative impacts families can have on mental health. Some research has considered more positive influences and this review aims to gather this information to discover how families can support individuals with psychosis, so that mental health services can build upon these.

Method

A systematic search of articles published from 1974 to 2016 found research investigating positive factors in families affected by psychosis. The quality of the articles was graded according to a traffic light system which was informed by quality criteria from Elliott, Fischer, and Rennie (1999); and Young & Solomon (2009). All but one of the studies attained a green or orange colour indicating a good or reasonable standard of research. The essential information from each article was summarised and integrated to aid the reader in finding out the broad messages.

Results

17 articles were identified and inspected. Themes clustered around five broad areas of positive family environments which were presented in this review as questions. These consisted of: 1. Can family factors have a positive effect on service user outcome?; 2. Who can help?; 3. What constitutes a positive environment?; 4. How can we recognise positive outcomes/environments?; and 5. What factors can affect family functioning?

Conclusions

The articles suggested that positive family environments can significantly influence and support mental well-being. Specific elements of positive environments included warmth, regular contact, positive remarks and behaviours, positive emotions, emotional involvement and family cohesion. The influence of the whole family was important, not only a key individual. Furthermore, high levels of parental emotional involvement could be helpful where it is age and culturally appropriate. Clinical interventions that aim to modify family

interactions could benefit from emphasising the cultivation of warmth and positive relations within families as a central part of their approach.

EMPIRICAL RESEARCH: EXPLORING FAMILY EXPERIENCES AND
RELATIONSHIP DYNAMICS WHERE ONE MEMBER EXPERIENCES PSYCHOSIS:

“WE’VE BEEN ON THAT JOURNEY TOGETHER”

Background

Parents and families become an essential source of support for young people who experience mental health difficulties such as psychosis (Cresswell et al., 1992). Current research into families and psychosis tends to focus on how negative family relationships impact symptoms (Miklowitz, 2004) and the burden families experience as a result of caring (Saunders, 2003). Research generally neglects to think about the family as a whole and lacks service user and siblings voices. Families as a whole, are mutually influenced by individual family members (Cox & Paley, 1997). Therefore this study aimed to attain a comprehensive, more nuanced account of family experiences during an episode of psychosis by recruiting several members of the same family to facilitate gaining an understanding from a multiple perspective approach. It was important to interview the individuals who had experienced psychosis as well as their siblings and parents where possible, to get the perspective of different people within the family. There were two research aims which underpinned the study. The first a question: How are relationships and roles within families experienced when one person experiences psychosis? And a secondary research aim to identify the adaptive, positive ways in which families adjust and cope.

Method

16 individuals from five families of adolescents experiencing a first episode of psychosis (FEP) were recruited from a local specialist mental health service. Participants were

interviewed individually using a pre-prepared, semi-structured interview schedule which helped to develop a discussion. Participants were asked to reflect on their experiences of the family environment before, throughout and after the episode. Interviews were transcribed verbatim and the analysed using Interpretative Phenomenological Analysis (IPA), a recognised method for interview analysis. IPA was chosen as it prioritises the perspective of the participant and aims to understand their experience and their context in order to give a faithful account of their interview.

Findings

Three overarching themes were developed which described methods that families used to manage changes that had occurred as a result of psychosis. These themes were: adapting through learning and communication; unity, sharing and delegating; and damage, repair and revisiting. See table 10. below for a summary of these themes.

Table 10.

Summary of themes

Superordinate theme	Subtheme
Adapting through learning and communication	<p>Most families were unfamiliar with psychosis and spoke of learning about their loved one's experiences, the diagnostic label and how to cope and help them. They found that this helped them understand what was happening for their relative and often made them more tolerant and sympathetic.</p> <p>Families expressed that communicating well with each other could be challenging, but important. Sometimes participants felt unsure whether to share their experiences with relatives or friends because they were worried about stigma but they also thought about how it might help others in a similar situation.</p> <p>Families talked about valuing social support in helping them understand and cope, e.g. mental health services, carers groups, church community or friends.</p>
Unity, sharing and delegating	<p>Participants conveyed a sense that the family is a unit and each person is affected by each other, so when one is ill, everyone is affected. While the FEP was very difficult to manage, many said that their relationships had grown stronger as a result.</p> <p>Some talked about everyone having a role that was their responsibility and contributed to an overarching family goal, but this was flexible and if it was easier for someone else to take up that task, that generally happened without upheaval.</p> <p>Usually two individuals within the family had a particularly close relationship that was a special connection. They might share interests or private things and enjoyed a unique bond. Other family members used a common interest to facilitate spending time together.</p>
Damage, repair and revisit	<p>All families found their experience of FEP to be difficult. Sometimes this brought on conflict or difficulties in relationships, but some described how other relatives might make efforts to repair these difficulties. Many families perceived their loved one as more vulnerable and dependent on them than before. Causing parents and siblings to take on a more intensive caring role before, even reminding them of earlier phases of childhood. For some parents or siblings this felt natural, others found it frustrating. Most adolescents with FEP appreciated this extra support, but at the time it could be experienced as annoying.</p>

Conclusions/ Discussion

Families actively managed individual developmental and intra-familial relational difficulties by sensitively responding and adapting accordingly. Difficulties arising from the FEP were noticed by all members of the family and it seemed that all members made active efforts to help, including younger siblings. The experience of this change was frequently stressful, however increased support was often appreciated by the service users as important and responsive to their needs. The families in this research appeared to be quite resilient as they were able to learn, adapt and grow as a result of their experiences, despite the significant challenge that this presented.

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Appendix C

Participant information leaflet.

This leaflet was given to potential participants by their key worker. For distribution the leaflet was printed double sided and presented in a tri-fold format.

Side 1

What if I want to take part?

Great! Please let me know either by contacting me (Charlotte Marriott) or by detailing it on the back of this leaflet. I'll ask the key worker to give me your details and I will get in touch with you.

What if my family don't want to take part?

It's entirely up to you, participation is voluntary. There will be several opportunities for you to change your mind. You or your loved one's care will not be affected.

If no one else in our family wants to volunteer, but you do, please let me know and I will be able to include you as an individual participant.

You are invited to take part in this research project.

Keep this leaflet, talk to others about it if you like. Ask me any questions, I'd be happy to hear from you.

Contact Charlotte

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Appendix C version Birmingham and Solihull
Mental Health NHS Foundation Trust

UNIVERSITY OF BIRMINGHAM

Charlotte Marriott

Research: Exploring family experiences and relationships when one member has psychological distress.

Want to find out what it's like for the whole family when one person has mental health difficulties? This will help mental health services know how to provide better support to families and individuals like you.

Printing:

Your printer might not print the same way our printers do, so make sure to try a couple of test prints. If things aren't aligning quite right, experiment with the Scale to Fit Paper setting. It's located in the Print dialog – just click Full Page Slides to get to it.

And did you notice we made fold marks for you? They are really light, but if you don't like them showing on your brochure, click View, Slide Master, and delete them before you print.

Customizing the Content:

The placeholders in this brochure are formatted for you. If you want to add or remove bullet points from text, just click the Bullets button on the Home tab.

If you need more placeholders for titles, subtitles or body text, just make a copy of what you need and drag it into place. PowerPoint's Smart Guides will help you align it with everything else.

Want to use your own pictures instead of ours? No problem! Just click a picture, press the Delete key, then click the icon to add your picture.

If you replace a photo with your own and it's not a flawless fit for the space, you can crop it to fit in almost no time. Just select the picture and then, on the Picture tools Format tab, in the Size group, click Crop.



Who is doing this research?

My name is Charlotte Marriott. I am studying for a doctorate at the University of Birmingham to become a Clinical Psychologist.

I already have a Masters degree in Clinical Psychology and have worked in Psychology for more than 5 years in the NHS and charitable organizations.

I am supervised by Dr Michael Larkin, Senior Lecturer at the University of Birmingham and the project has NHS ethical approval.

Why my family?

If you, or a member of your family has experienced mental health problems, then we want to hear from you.

Only you know what it is really like being in a family in this situation. We've understand more, we might be able to change services to help you, your family and others like you better.

We are looking for at least 3 members of your family who are aged 16+ to take part individually or in a group discussion.

What will we do?

If you want to take part, we will talk to you first and answer any questions you might have. You can change your mind at this point.

We will arrange a time and place that suits you, perhaps at your home, the University or Birmingham or an NHS site. We will then have a conversation in private or with your family in a group discussion about what it is like being in your family. This will be audio recorded and will last about an hour, unless you want to stop. We will ask you to sign consent forms. You can still change your mind for up to two weeks after the discussion.

We will also ask you some basic demographic details.



UNIVERSITY OF BIRMINGHAM

Confidentiality

An audio recording will be used to write out our conversation word for word. Names and identifying information will be changed to protect your privacy. Recordings and personal information will be kept securely and destroyed at the end of the research.

I might quote something you said in a report. We will check that is ok with you and will make sure no one else can tell it was you that said it.

I am required to share any details you give which raise concerns for the safety of yourself or others.

What will happen next?

After I have analysed all the interviews, I will write a report which will be assessed as part of my doctorate degree. You can access this through the University, but I would be happy to send you a summary. I hope to publish this in scientific journals, and to circulate my findings within the Early Intervention service to help develop their services.

Travel Expenses

It will be possible to reimburse you for costs involved in getting to the interview. If you change your mind about taking part, you will still be reimbursed.

What if I change my mind?

You can withdraw from the study without giving a reason at any time before or during the interview. After the interview, you can think about for up to two weeks. If you then contact us to see if you want to withdraw some or all of your data, again no reason needed. Withdrawn data will be destroyed.

Printing

Your printer might not print the same way our printers do, so make sure to try a couple of test prints. If things aren't aligning quite right, experiment with the Scale to Fit Paper setting. It's located in the Print dialog – just click Full Page Slides to get to it.

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If you replace a photo with your own and it's not a flawless fit for the space, you can crop it to fit in almost no time. Just select the picture and then, on the Picture tools Format tab, in the Size group, click Crop.

Appendix D

Participant Information Sheet

This participation information sheet was printed on local NHS trust headed paper and given to individuals who expressed an interest in volunteering for this study.

Information about the research

“Exploring family experiences and relationship dynamics where one member has psychological distress.”

I would like to invite you to take part in a research study. Before you decide, please read through this information on why the research is being done and what it would involve for you. Please feel free to talk to others about the study and contact me, Charlotte Marriott (contact details below) for more information. I will be happy to discuss the research with you. Please consider carefully, whether you wish to take part.

- *What is the purpose of the research?*

I want to know how family relationships work and change when someone in the family has mental health problems. My aim is to make sure that mental health services have a clear understanding of this so that they can provide more effective support to families like yours.

- *Why have I been invited to participate?*

You have been invited because you, or a member of your family is experiencing mental health difficulties and your family have been in contact with the Early Intervention Service. You may have seen an advertisement poster for the study, or a key-worker may have identified you

as a possible participant. It is completely up to you if you want to take part. I am hoping that three members from your family will take part. I aim to recruit around three families so that about nine participants in total will be included in the research.

- *Should I take part?*

It is entirely up to you! Participation is voluntary for all family members. Please go through this information sheet and ask any questions. This research does not affect your or your loved one's treatment or the service you receive in any way.

Because everyone has a different opinion, I would like to interview at least three family members, aged 16 or over. I would like to include the person who experiences mental health difficulties as well, but this is their choice and some members of the family may still take part even if others don't want to. If you agree to take part, I will then ask you to sign a consent form.

It is my responsibility to inform your consultant (*if* you are under the care of a Psychiatrist) if you decide to participate in the study. Again, I will be sure to get written consent from you to be sure that is ok. They will not receive details of our conversations, only factual information about the study.

You are free to withdraw at any time, without giving a reason.

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

If you decide to take part, we will arrange a time to meet that is convenient for you, at a place of your choice (like at your home, at the University of Birmingham or at an NHS address). I will ask you to sign a consent form to say that you agree to take part and we will begin a

research interview. This is an informal conversation where I will ask you some questions about how things work in your family and about whether your relationships have changed over time, and in what way. This conversation will probably take around 60 minutes. Because everyone has a different opinion, I would like to interview at least three family members, aged 16 or over.

- *What will happen to the information?*

Because I can't remember everything you say in this conversation, I will take an audio recording of our discussion so that I can write it down afterwards (a transcript). This will help me analyse all the conversations I have with the participants in the study. Your information will be collected and stored to adhere to ethical and legal standards and you can expect that it will be handled in confidence. The recording will be destroyed once the project is complete and written up.

This analysis will be written and assessed as part of my doctoral research. I also intend on publishing it and presenting the outcome for the benefit of other mental health professionals and researchers. I would be happy to send you a summary of the research if you would like, it will also be possible to access the completed research project through the University of Birmingham.

- *Is what I say private?*

Yes. To make sure no one can find out what you said, I will change all names and identifiable information. My supervisor will look at the transcripts and I will use anonymized direct quotes in the final report. No one outside of the study will be able to tell that you said it, apart from you. Your real name will not be used but it may be possible for your family to recognize

something you have said. We can make extra efforts to keep it anonymous or we can leave it out. I will work with you to make sure you are happy about how your contribution is used. I am obliged to share the contents of our discussion if I have reason to worry about the safety of you, or others. I will discuss this with you if the need arises.

- *Can I change my mind?*

Yes! You don't even have to give a reason and your contribution will be destroyed, no questions asked. You can withdraw before or during the interview. You can also withdraw up to two weeks after the interview. You can withdraw your entire contribution, or specific bits of it. Two weeks after the interview, I can give you a call to check that you are happy for me to go ahead or whether you have decided to withdraw from the project. None of this will affect the care you or your relative are receiving from the Early Intervention service.

- *Travel expenses and payments*

I can reimburse travel costs for you if you decide to take part in this project. If you decide later on that you want to withdraw your participation you will still be reimbursed for travel costs. Unfortunately, I can't reimburse you for any time taken off work to take part.

- *What are the possible disadvantages and risks of taking part?*

The discussion may prompt you to recall difficult memories and to reflect on potentially distressing life changes for yourself and your family.

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

I cannot promise the study will help you but the information I get from this study aims to improve the services for and treatment of people in a similar position. You may find it helpful to consider the strengths in your family and the positive, as well as the negative aspects of your circumstances. You may find yourself empathising with your family members more as a result of thinking about their perspective.

- *What if there is a problem?*

If you have a concern about any aspect of this study, you should speak to the researcher who will do their best to answer your questions (contact details below). If you remain unhappy and wish to complain formally, you can do this by contacting the Patient Advice and Liaison Service (PALS). Details can be obtained from the PALS leaflet.

- *Who is the researcher?*

My name is Charlotte Marriott. I have worked as an Assistant Psychologist with people with mental health problems and their carers for 5 years. I have a Masters in Clinical Psychology research. Now I am training to be a Clinical Psychologist at the University of Birmingham.

Michael Larkin is supervising me in this project. He works at the University and has been doing this kind of research for 13 years now.

The project has ethical approval from the NHS and Birmingham University and I have passed all the necessary criminal records checks to work with children and vulnerable adults.

Thank you for taking the time to consider this research study. If you think you might be interested in taking part, you can contact me to talk about it more. I would be very happy to answer any questions you might have. We can talk over the telephone or I am happy to

arrange a time to meet if you prefer.

You can contact me at any time on: Tel: [REDACTED] or Email: [REDACTED] or

you can let your key worker know and they will pass the message on.

Kind regards,

Charlotte Marriott

Appendix E CONSENT FORM

Participant Identification Number:.....

CONSENT FORM

Title of Project: Study 1. Exploring family experiences, roles and relationship dynamics where one member has psychological distress.

Researcher: Charlotte Marriott

Please initial box

- 1. I confirm that I have understood the information sheet dated (version ...) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time during the research interview, without giving any reason, without my own or my loved one's medical/social care or legal rights being affected.
3. I understand that the research interview will be audio-recorded
4. I understand that following the research interview I will have a two-week period for reflection. The researcher will then contact me at which point I may withdraw my interview entirely or in part, without giving any reason, without my own or my loved one's medical/social care or legal rights being affected.
5. I understand that the data collected during this study will be looked at by the researcher and relevant others at the University of Birmingham to ensure that the analysis is a fair and reasonable representation of the data. Parts of the data may also be made available to the NHS team responsible for me or my family member's care but only if any previously undisclosed issues of risk to me or my family member's safety should be disclosed.
6. I understand that direct quotes from my interview may be published in any write-up of the data, and used for training purposes, but that my name will not be attributed to any such quotes and that I will not be identifiable by those outside of my family by my comments.
7. I agree for my Psychiatrist to be informed of my participation (Only applicable if you are under the care of a Psychiatrist)
8. I agree to take part in the above study.

Name of participant

Date

Signature

.....
Name of researcher

.....
Date

.....
Signature

Introduction

Thank you for coming today. What I would like to do is to learn a bit about what it is like at the moment to be in your family. I know that [patient name] has been experiencing some difficulties and I was wondering how that changed things for them and everyone else at home. I have a list of questions here – we don't have to get through them all, they are just prompts to help us along and get us thinking.

Do you have any questions before we start? Data protection, storage etc. This research is not a therapeutic discussion and will not influence care.

General introductory questions about family as a whole

1. Who is in your family?

2. What is the atmosphere like at home?/ What is it like to live in your home?
 - a. What makes it like that?
 - b. How did it get to be like that?
 - c. Do you have fun together?/ Do you have a laugh together?
 - d. Has that been different in the past?

3. Have [family member's] mental health problems changed anything about your family?

4. What have been the ups **and** downs in the past year? (Assumption that they will talk in relation to the mental health of the service user, prompt if not, also prompt if miss positive or negative aspects)

Alliances & Relationship Dynamics

5. Who would you say you are closest to?
 - a. Can you tell me a bit about your relationship?
 - b. Can you give me an example (of how they support you etc.)?
 - c. How are they important to you?
 - d. Do you have things in common?
 - e. Has it always been like that?
 - f. (if not) When did things change?
 - g. How do you think they feel about you?
 - h. Do other family members know?
 - i. How do they know?
 - j. What do they think about that?

6. Can you tell me a bit about (each other family member) and the service user's relationship with them?
 - a. How are they important to them?
 - b. How do you think they feel about them?
 - c. Has it always been like that?

7. When did/do things change? Do you think how [family member] is feeling has anything to do with that?
 - a. How did you get on when you were younger?
 - b. Do you think you'll always get on with them like that?

8. Who would you say they are closest to?
 - a. How do you think it helps them to have someone particularly close?
 - b. How/What do you imagine they feel/think about that?
 - c. How do you feel about that?
 - d. How do other members of the family feel about that?

9. Are there any difficult relationships in the family?
 - a. How do you know?
 - b. Has it always been like that?
 - c. When did/do things change?
 - d. How do you feel about it?
 - e. How do they and other family members feel about it?

Roles

10. Where/How do you see yourself in the family?
 - a. What do you see your role as?
 - b. Are there things that are your responsibility? Particularly to do with the affected family member? And other family members?
 - c. Who else knows that you do this?
 - d. Has it always been like that? When did it change? Why?

e. How do you feel about that?

11. Who takes care of you? - Emotionally/Financially/Practically

a. How do they do that?

b. Has it always been like that? When did it change? Why?

c. How do you feel about that?

12. Who do you take care of? - Emotionally/Financially/Practically

a. How do you do that?

b. Has it always been like that? When did it change? Why?

c. How do you feel about that?

13. Is it different being in your family, compared to how you see other families?

Additional questions

14. Is there anything else or anyone else you want to tell me about what it is like to be in your family?

15. How did you find our conversation today?

16. Has it left you with any particular feelings or thoughts?

17. Do you have any questions before we finish?

Appendix G

Example of line-by-line analysis

R TAKES PHONE TO WIFE IN OTHER ROOM

Before - acute
vs
after

R: err, what's it like to live in this house or I think you said home, erm so yes, yes

stress due to lack of understanding, affected behaviours in negative way?

less stressful than it used to be erm during sort of the acute-phase and then maybe the run-up to the acute-phase. Er a lot trickier, a lot more stressful...erm partly because we didn't understand or appreciate Michael's problem, erm, we acted in certain ways. Now we're slightly more understanding of it, it's easier for us to adapt our behaviour we to, after family therapy sessions, that's been quite helpful

BST ++

I: ok

Learned & matured in how to relate to each other

R: erm, And I think we've just become more [laughs] mature in our dealings with each other probably [laughs]

I: Okay, do you have fun together as a family?

Fewer activities as family when SCT unwell. Fewer activities associated with enjoyment together

R: erm, yeah, more than we er had in recent times I suppose, so we, we do go out now as a family, erm... dinner occasionally, we go and visit family, we did less of that maybe with all of us going, er we were in London, Wimbledon the last couple of days, we, so we do manage to get holidays in erm and they've been more difficult because Michael has been reluctant to be a part of, you know, just going out, seeing other people, gets a bit anxious, get worried. We didn't appreciate that, we just thought he was being awkward and you know, as, as I

M's MH issues prevented unified activities/experiences -ve attribution = bad feeling

lack of understanding about sons difficulties = negative attribution about him

improvement =

↑ understanding

↑ support of ^{him} said, as we learned more, we can support each other, and Michael has improved

= he improves anyway so, Yeah we do have fun as a family, it's good.

= more fun / time together / activities as family

I: Okay and would you say that Michael's mental health problems have changed anything about the family, about your family?

R: About, about the four of us?

I: mmm

Positive family outcome from episode = considerate

R: Thinking of that family unit, er yep, I think so I think we're um ... more

unity

experience (related to knowledge + understanding) + resilient Help each other / mutual support

considerate of...erm his worries, his anxieties, er with probably a little bit more

more experienced and resilience to our stress levels erm so yeah, we probably

changed a bit, we still have our moments were it gets quite 'argh' erm tense, not perfect - tension, relationships

but I think maybe we have less of those now and we help each other when we're tense, so if I get a bit stressed, and we'll sort of talk me through well actually you frequently of arguments

know "think about the improvements", then equally if Caroline's stressed then,

you know, we try and help each other and so, because of the family sessions, we BFT +

understanding sensitive

can appreciate different aspects erm and when you're stressed you tend to think

less clearly

Helper - Helped role when one is stressed, other slips into helper role.

I: mmm

improvement =
↑ understanding

↑ support ^{of} said, as we learned more, we can support each other, and Michael has improved

him
= he improves anyway so, Yeah we do have fun as a family, it's good.

= more sons/time together/activities
as family

I: Okay and would you say that Michael's mental health problems have changed anything about the family, about your family?

R: About, about the four of us?

I: mmm

Positive family

outcome from episode

= considerate, experience related to knowledge + understanding?

+ resilient help each other / mutual support

R: Thinking of that family unit, er yep, I think so I think we're um ... more unity

considerate of...erm his worries, his anxieties, er with probably a little bit more

more experienced and resilience to our stress levels erm so yeah, we probably

changed a bit, we still have our moments were it gets quite 'argh' erm tense, not perfect - tension, relationships

but I think maybe we have less of those now and we help each other when we're

tense, so if I get a bit stressed, and we'll sort of talk me through well actually you minimising frequently or arguments

know "think about the improvements", then equally if Caroline's stressed then,

you know, we try and help each other and so, because of the family sessions, we BFT +

understanding sensitive

can appreciate different aspects erm and when you're stressed you tend to think

less clearly

Helper - Helped role when one is stressed, other slips into helper role.

I: mmm

Appendix H

Example development process of family themes into superordinate themes.

Family level themes were identified by colour. Superordinate themes were developed through grouping conceptually similar themes across families.

