Journeys into Recovery:
Family Narratives of First Episode Psychosis and Behavioural Family Therapy

Rachael Sarah Edge

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CANDIDATE DECLARATION

Title of degree programme	Doctorate in Clinical Psychology
Candidate name	Rachael Sarah Edge
Registration number	11027446
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Declaration and signature of candidate
I confirm that the thesis submitted is the outcome of work that I have undertaken during my programme of study, and except where explicitly stated, it is all my own work. I confirm that the decision to submit this thesis is my own. I confirm that except where explicitly stated, the work has not been submitted for another academic award. I confirm that the work has been conducted ethically and that I have maintained the anonymity of research participants at all times within the thesis. Signed: Date:

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Finally I am very grateful for the support and understanding of my family and friends while I completed this thesis.

Note to Readers

This thesis consists of three papers: a literature review paper, an empirical research paper, and a reflective review paper.

The literature review paper will be submitted for publication in the Early Intervention in Psychiatry Journal, which has an impact factor of 1.653. The journal's aims and scope are as follows:

> *Early Intervention in Psychiatry* publishes original research articles and reviews dealing with the early recognition, diagnosis and treatment across the full range of mental and substance use disorders...The journal provides comprehensive coverage of early intervention for the full range of psychiatric disorders and mental health problems, including schizophrenia and other psychoses, mood and anxiety disorders, substance use disorders, eating disorders and personality disorders.

The empirical research paper will be submitted for publication in the Journal of Family Psychology, which has an impact factor of 1.577. The journal description is as follows:

> *Journal of Family Psychology* offers cutting-edge, groundbreaking, state-of-the-art, and innovative empirical research with real-world applicability in the field of family psychology. This premiere family research journal is devoted to the study of the family system, broadly defined, from multiple perspectives and to the application of psychological methods to advance knowledge related to family research, patterns and processes, and assessment and intervention...

The reflective review paper is not intended for publication; this presents a reflective account and critique of decisions made throughout the creation of this thesis, as well as an extended discussion of points of interest.

The papers are presented in the format required for submission of this thesis, and on submission for publication will be reformatted in line with each journal's requirements. See Appendices C.6 and C.7 for author submission guidelines for each journal. The referencing system used by each journal has been adhered to; for the literature review, the Vancouver system is used, and for the empirical research paper, American Psychological Association (6th Edition) style is used. The latter style is retained in the reflective review paper.

Abstract to the Thesis

This thesis explores the journeys undertaken by families when someone experiences a first episode of psychosis (FEP), and the family seeks help and receives treatment. A review of the literature on families' experiences of help-seeking for FEP provides a focus on the beginning of this time. The literature is synthesised to reveal a journey through the early help-seeking experience, and the extent to which experiences are shared between carers and individuals with FEP is explored.

The empirical research paper provides insight into families' experiences further along on their journey; presenting a qualitative study on family narratives of FEP and Behavioural Family Therapy (BFT). Families completing BFT were interviewed, and narrative analysis was used to identify their shared narratives and the subplots within these. A broad narrative of the journey from illness to recovery is presented, with subplots within each broad phase of the journey considered. The extent to which narratives can provide evidence of effectiveness in BFT is explored, as well as consideration of how such narratives may aid recovery. The role of parental power in maintaining family narratives is considered, and further research and clinical implications are discussed.

The reflective review paper presents a reflective background and critique of the literature review and empirical research study, as well as an extended discussion of some points within these. The author's journey through the creation of this thesis is presented, within the wider context of clinical psychology research. Decisions made during creation of the thesis are elucidated, and the limitations and value of the thesis are considered. This reflective journey begins with the author's own epistemological position, and consideration of how this influenced the thesis, and ends with consideration of personal learning points gained during completion of the thesis.

Paper 1

Literature Review Paper

Families' Experiences of Help-Seeking during a First Episode of Psychosis.

Word count:

Abstract =237

Report = 5036

Total = 5273

Preface to the Literature Review

Definition of Terms

Individual, carer and family.

Many terms have been used to describe those who experience a first episode of psychosis (FEP), and the family, friends, or otherwise who are involved in their informal care and help-seeking. For consistency, the term 'individual' will be used in reference to those who have experienced FEP and 'carer' used to describe those providing informal care. The term 'family' will be used to describe the whole family, including the individual and carers.

First episode psychosis.

Breitborde at el[1] identify varying operational definitions of FEP, arguing that the term is ambiguous and variance restricts the extent to which findings relating to FEP can be integrated. Acknowledging this limitation, and to enable consistency, use of the term FEP is intended to cover any definition of first or early psychosis used in the literature, whether this leads to a diagnosis of a specific psychotic condition, such as schizophrenia, or not. This is reflected in the search terms used for the literature search. Help-seeking during a first episode of psychosis is likely to involve the same processes, regardless of eventual diagnosis.

Help-seeking.

In order to enable a focused synthesis of a specific part of families' journeys during FEP, help-seeking is defined as active help-seeking from informal sources, such as family, friends, or professionals, and from formal health and mental health sources. While the literature in this area may include duration of untreated psychosis, help-seeking behaviour, and intervention experiences, these are beyond the scope and focus of this review.

Abstract

This review synthesises the research literature on help-seeking experiences of individuals with a first episode of psychosis (FEP) and their carers. Early intervention following or during FEP has been demonstrated to improve long term outcomes, and research has explored factors influencing delays in seeking help. However, despite national guidance and public health campaigns aimed to increase early help-seeking for FEP, access to services can be delayed. Research into help-seeking experiences has been broad, including at one end of the journey, help-seeking delays in individuals, and at the other, experiences of intervention. A focus on active help-seeking aims to better understand what happens to families when they are attempting to access help during FEP.

Accordingly, nine papers on help-seeking experiences were reviewed. The literature search strategy demonstrates how these papers were selected, and an overview and collective methodological critique elucidates the quality of the literature in this area. Findings from the literature are synthesised to explore family experiences of help-seeking during FEP. Some help-seeking experiences are common to individuals with FEP and their carers, such as confusion about where to access help, difficulties obtaining adequate support from doctors, failed help-seeking attempts leading to crisis points, and the importance of support from others during help-seeking. However, help-seeking experiences can be inharmonious within families, with differing ideas about what should be done. The dominant and less prevalent stories of help-seeking are summarised, and finally, future research directions are discussed.

Introduction

This review examines the literature on help-seeking experiences during a first episode of psychosis (FEP). FEP is introduced within the context of policy and research, then the literature search strategy demonstrates how nine papers were selected for review. An overview and methodological critique of these papers reviews the quality of the literature in this area. Finally a synthesis of findings presents the journeys experienced by families during help-seeking for FEP.

First Episode Psychosis

Psychosis is not a standalone diagnosis, but describes the symptoms of psychotic conditions, such as schizophrenia.[2] Increasing acknowledgement that those who were traditionally diagnosed with schizophrenia can recover[3] has influenced a shift towards identifying and treating psychosis, with recognition that this does not inevitably indicate or require a more pervasive diagnosis.[4] Hence, FEP - the term often used to describe a first psychotic episode, has become a focus for service development, research and intervention.[5]

The National Institute for Health and Care Excellence (NICE)[6] describes a prodromal phase which often precedes FEP, during which positive and negative symptoms associated with schizophrenia, though not as severe, are experienced.[5,7] The acute phase of psychosis is usually associated with florid psychotic symptoms,[7] which are often a worsening of previously attenuated symptoms.[5]

Policy and Guidance

Since the 1990s, research into prevention of psychosis has increased,[8] and numerous studies have demonstrated the efficacy of early intervention (EI). EI improves outcomes and reduces severity of problems in the long term,[9–12] improves chances of returning to employment and education,[12] and increases remission rates.[13,14] In 2001, the Department of Health (DH)

outlined a model for EI services in the UK in the Policy Implementation Guide.[12] This included raising awareness and monitoring of psychosis symptoms, and clear and rapid referral pathways. Community support was recommended over hospitalisation whenever possible, and family support and collaboration was suggested to improve assessment and outcomes. Subsequently, the International Early Psychosis Association (IEPA)[15] provided clinical practice guidelines for early psychosis. These included increasing community awareness, competency in primary health settings in recognising and responding to FEP, easily accessible and flexible specialist services, and prioritising family engagement. Providing services prior to crisis point is considered best practice; reducing the likelihood of involuntary and invasive interventions. The DH has recently announced an aim to provide help for those with FEP within two weeks of presentation,[16] and both Rethink[17] and The Schizophrenia Commission[18] emphasise the need for increased investment in EI services.

Research on Help-seeking

This emphasis on EI arises from and perpetuates a wealth of research into factors delaying access to services, thus increasing the duration of untreated psychosis (DUP); the period from first psychotic symptoms to adequate intervention.[19] Longer DUP leads to more symptoms, lower quality of life, and worse functioning at 6 months, decreasing the likelihood of remission.[19] Research on delayed access to EI for FEP identifies two broad contributing factors: help-seeking delays, and health system delays.[20–22]

Help-seeking delays.

A systematic review of the literature on help-seeking by carers found delayed recognition of illness, misattribution of symptoms, and failure to recognise the need for help as factors contributing to help-seeking delay.[23] A similar meta-synthesis described a period of 'not knowing' (p.8), where carers looked for answers, only seeking professional help when distress intensified.[24] Other barriers to help-seeking include stigma, whether perceived or actual,[23,25] deterrence of help-seeking by those with FEP,[23,24] and individuals hiding

their symptoms.[26] The actions of others are therefore instructive in facilitating early access to help.

Health service delays.

Mental health service delays, often in secondary care, have been found to contribute most to delays in accessing EI services, followed by delays in help-seeking.[21] Younger individuals are also more likely to experience delays in access to services.[22] Service barriers can include limited availability of services, appointments, and staff, and communication difficulties.[23]

Help-seeking pathways and experiences.

Further research presents broader experiences and pathways of help-seeking. A systematic review explored the literature on formal pathways to care;[27] however, pathways of informal help-seeking were omitted. More comprehensively, a recent meta-synthesis presented a 'higher order' (p.11) concept of help-seeking experiences of carers.[24] This described an interaction between a period of sense making and seeking answers, a crisis point, and the impact on the carer. Help-seeking is most likely to occur during the acute phase of FEP,[7,8] with help-seeking attempts boosted during a crisis.[23,24] While crises can facilitate access to services,[23] numerous unsuccessful help-seeking attempts may precede the actual provision of help.[28,29]

As others are more likely to recognise the need for help during FEP,[30,31] it is often carers who initiate help-seeking. The majority of the literature focuses on carers' perspectives of help-seeking, with the individual sometimes featuring as a barrier to this process. The recent reviews in this area[23,24] provide valuable descriptions of carers' broad experiences of help-seeking, including pre-help-seeking experiences. However, much less is known about individuals' experiences of help-seeking, and about the shared journey made by families during this time.

Rationale for the literature review

While help-seeking during FEP is likely to impact on the whole family, the literature focuses mainly on carers' experiences. Consideration of how individual and carer experiences converge to create an overall family experience is lacking, despite evidence that family dynamics are implicated in both the development of and recovery from psychosis.[32,33] Further, in the literature 'help-seeking' often includes periods when help is not being sought, confusing the definition of this term. This review presents a focused synthesis of the collective experiences of individuals and carers during the time they actively sought help for FEP. This is limited to the period when personal barriers to help-seeking have been overcome, and active help-seeking occurs, both informally and formally. The dominant narrative of this experience will be explored, with consideration of how this differs and coalesces for individuals and carers, and with consideration of other, less prevalent stories.

Method

Objectives of the Literature Review

This traditional critical literature review, intended to consider the collective family experience during help-seeking for FEP, had the following aims:

- to explore individuals' and carers' experiences of help-seeking during FEP;
- to consider the extent to which these experiences are shared by individuals and their carers; and
- to review the quality of literature in this area.

Search Strategy

The inclusion and exclusion criteria for the literature search were as follows:

Inclusion criteria.

- English language papers from any year.
- Literature on individuals' and/or carers' experiences of help-seeking, which represents their perspective.
- Literature on experiences relating to active help-seeking in response to FEP.
- Peer reviewed papers.
- Book chapters.
- Unpublished theses.
- Conference proceedings.
- Surveys.

Exclusion criteria.

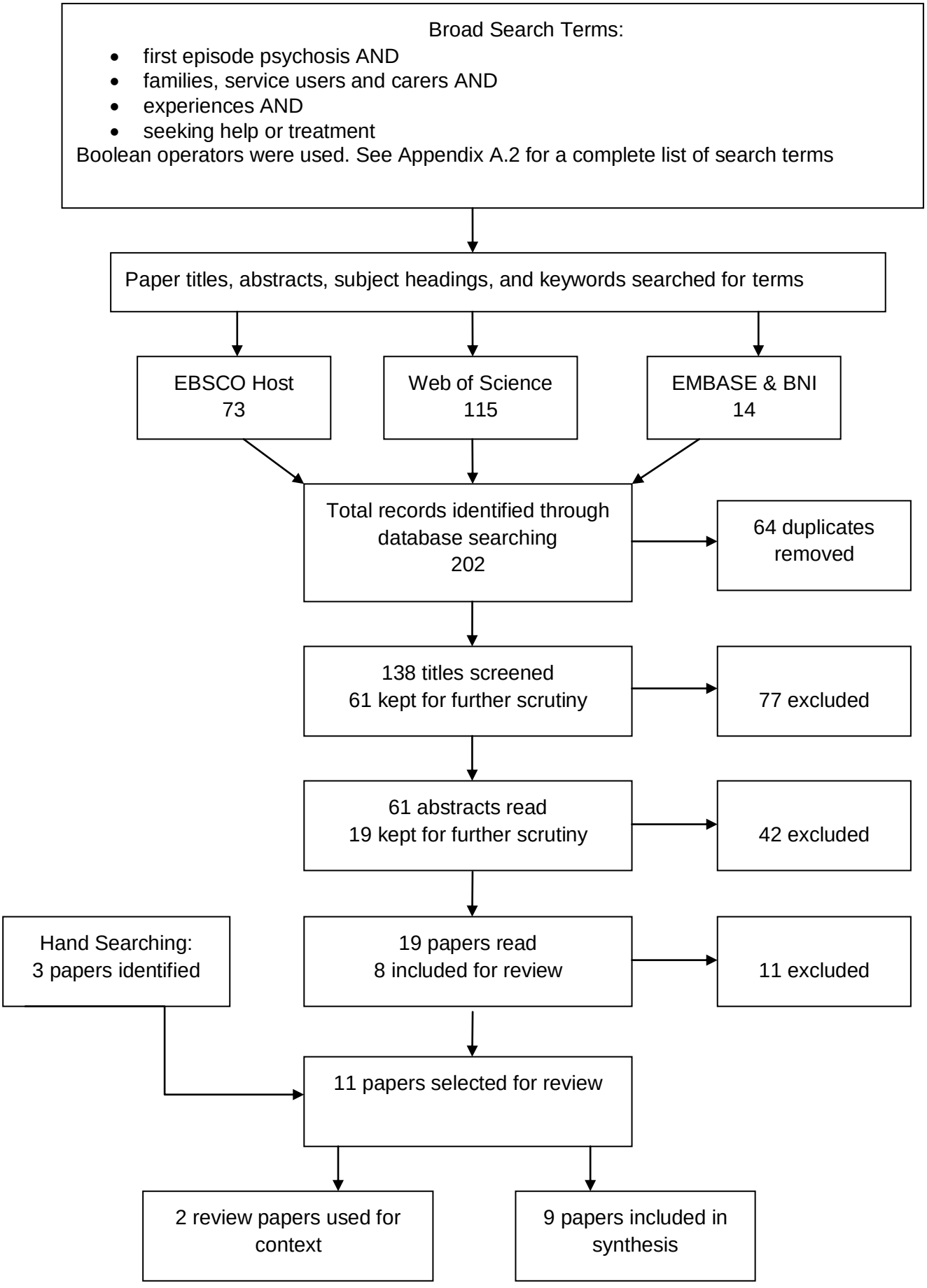
- Literature focusing on intervention or recovery in FEP.
- Literature focusing on DUP, personal help-seeking delays, or help-seeking behaviour.
- Literature which does not represent the individual or carer perspective.
- Literature on drug induced psychosis.
- Book or other reviews.

Electronic databases with a focus on health and life sciences were searched (See Appendix A.1), in addition to hand searching. Results were scrutinised against inclusion and exclusion criteria. Figure 1. provides details of the search strategy and results.

The literature search strategy and results were cross validated by a second researcher, to ensure results were obtained in a rigorous and systematic manner.

Two of the 11 selected papers were review papers; a meta synthesis[24] and a systematic review.[23] These reviews adopted a broader definition of help-seeking, and only considered carer experiences. Those papers they included which met the present search criteria are included in this review;[35-42] while there is duplication of some papers, the present synthesis of individual and carer experiences is markedly different to the synthesis of purely carer experiences presented in these reviews. The review papers have not been included within the critique and synthesis, but are used to give context to this review.

Figure 1. Diagrammatical representation of search strategy and results



Review of the Literature

Overview

Studies were undertaken in Canada,[34,35] the USA,[36,37] the UK,[38,39] Australia,[40] New Zealand,[41] and Hong Kong[42]. Participants from a range of ethnicities and gender were recruited. Participant numbers ranged from 5-58. Six studies[35–38,40,42] concerned carers' experiences only, one study[34] explored individuals' experiences and two studies[39,41] explored both individuals' and carers' experiences.

All used a qualitative methodology, despite methodology not being restricted in the literature search. Qualitative methods are best suited to exploring experiences, which may account for this result. Data collection methods involved semi-structured interviews,[35,36,38–40,42] open ended interviews,[37] or a combination of structured and unstructured interviews.[34,41] Analysis methods included grounded theory[38], interpretative phenomenological analysis (IPA),[40] thematic analysis,[35,39] general inductive approach,[41] content analysis,[36,41,42] and an undefined phenomenological approach.[37]

A brief overview of each study is provided (See Table 1. for further information):

Bergner et al[36] interviewed 12 African American family members for accounts of seeking help for a loved one experiencing FEP. Content analysis elicited four themes; one of these was relevant, describing system factors in treatment delay.

Wong[42] interviewed 58 Chinese caregivers about help-seeking during early psychosis and employed content analysis; findings relating to initiation of help-seeking and responses of helpers were presented in statistical and qualitative form.

For her thesis, Pearse[38] interviewed 16 relatives, using grounded theory to propose an integrated theoretical framework of help-seeking during the initial episode of schizophrenia. Two of the four main themes related to experiences of help-seeking: 'Communication and interaction' and 'Action'. Categories of 'help-seeking', 'Independence vs. over-intrusiveness',

'Knowledge', and 'Experience of professionals' were also relevant, as well as codes relating to individuals' willingness to get help.

Gerson et al[37] interviewed 14 family members of inpatients with 'recent-onset psychosis', revealing experiences of help-seeking through phenomenological analysis. The authors presented findings altogether, without the use of themes.

McCann et al[40] interviewed 20 Australian caregivers about their experiences accessing FEP services. Using IPA they identified three competing themes relating to help-seeking experiences: GPs as resourceful or unresourceful; carer barriers and service barriers; and enhanced experiences.

Czuchta et al[35] interviewed five parents of those with a 'first episode of schizophrenia' about their help-seeking experiences, using thematic analysis to identify three themes. Two of these related to help-seeking experiences: 'Continuous help-seeking' and 'Impact on parents'.

Anderson et al[34] highlighted a scarcity of qualitative research from individuals' perspectives. English and French speaking Canadians were interviewed for their experiences of obtaining care for themselves following FEP. Content analysis revealed five themes: lack of knowledge about psychosis symptoms and available services; self-stigma preventing help-seeking; significant others being crucial in initiating access to services; misunderstanding and loss of control, and unexpected benefits.[34] A table of advice from participants was also presented.

Finding an absence of literature in this area relating to under 18 year-olds, Cadario et al[41] interviewed 12 adolescents and 12 carers for experiences of accessing help following FEP. A general inductive approach elicited six themes, four of which are relevant to this review: lack of awareness; services approached; experience of services; and beliefs and knowledge of mental illness.

Tanskanen et al[39] interviewed 21 service users and nine carers about experiences during FEP, including the role of networks during help-seeking. Thematic analysis revealed five themes, four of which are relevant to this review: 'help-seeking processes'; 'beliefs and knowledge about mental health

services'; the social network's response; and 'health professionals' responses'.[39]

Table 1. Overview of studies

Authors	Study Title	Year and Country	Sample	Aims	Method
Pearse[38]	A qualitative study exploring relatives' experience of seeking help for a person during the early stages of schizophrenia.	1998 UK	Carers. 16 relatives of individuals with schizophrenia - half men and half women with schizophrenia. Aged between 18-40. Most were female (N = 13), and most were parents (N = 14). Ethnicity not provided.	• To understand families' role in helping a relative with an initial episode of schizophrenia receive services. • To explore the experience of making contact with services. • To understand whether gender of person with psychosis impacts help seekers experiences.	*Recruitment* Recruited by criterion sampling from a mental health service. *Data Collection* Semi structured interviews. *Analysis* Grounded Theory.

Czuchta et al[35]	Help-seeking for parents of individuals experiencing a first episode of schizophrenia.	2001 Canada	Carers. 5 parents of hospitalised children. More specific sample information is not available, as those interviewed sample formed part of a larger survey sample, the results of which are beyond the scope of this review. The majority of the larger sample were female, with a mean age of 49.7 years.	To examine factors affecting parental help-seeking following their child's first episode of schizophrenia.	*Recruitment* Convenience sample recruited from a hospital. *Data Collection* Semi structured interviews. *Analysis* Thematic Analysis.
Wong[42]	Uncovering sociocultural factors influencing the pathway to care of	2007 Hong Kong	Carers. 58 caregivers of relatives experiencing early psychosis.	To examine pathways of help-seeking in Chinese caregivers of relative with early psychosis,	*Recruitment* Convenience sample recruited from a specialist

	Chinese caregivers with relatives suffering from early psychosis in Hong Kong.		Aged between 20-68, predominantly 40-68. Most were female (N=48), and most were parents (N=51). All were Chinese.	and explore what shapes help-seeking patterns.	service. *Data Collection* Semi structured interviews. *Analysis* Content Analysis.
Bergner et al[36]	The period of untreated psychosis before treatment initiation: a qualitative study of family members' perspectives.	2008 USA	Carers. 12 family members of an individual who had experienced psychosis. Aged between 32-62 years, with a mean of 47.8 years. Most were female (N=9), and most were parents (N=9). All were African American.	Different aims given within paper. One aim was to explore family members' accounts of seeking treatment for a loved one experiencing FEP.	*Recruitment* Recruited from participant pool of an ongoing research project. *Data Collection* Semi structured interviews. *Analysis* Content Analysis.

Gerson et al[37]	Families' experience with seeking treatment for recent-onset psychosis.	2009 USA	Carers. 14 family members of inpatients with recent-onset psychosis. Most were female (N = 10) and parents (N = 12). Ages not provided. An ethnic mix is alluded to but not detailed.	To understand treatment seeking experiences of families of young people with recent onset psychosis.	*Recruitment* Convenience sample, recruited from a psychiatric institute. *Data Collection* Open ended interviews. *Analysis* Phenomenological.
McCann et al[40]	First-time primary caregivers' experience accessing first-episode psychosis services.	2011 Australia	Carers. 20 primary caregivers of a young person with FEP. Aged between 21-76, with a mean age of 49. Most were female (N = 17).	To explore the lived experience of primary caregivers of young adults with FEP, focussing on how they accessed specialist services and overcame barriers.	*Recruitment* Recruited from a specialist FEP service in Australia. *Data Collection* Semi structured interviews.

					Analysis IPA.
Tanskanen et al[39]	Service user and carer experiences of seeking help for a first episode of psychosis: a UK qualitative study.	2011 UK	Carers and Individuals. 21 service users who had FEP, with a mean age of 26.5. Most were male (N = 15), and there was a mix of ethnicities - a relatively equal amount of white British, white other, black African, black Caribbean, and Asian Bangladeshi, with a smaller amount of mixed race participants. 9 carers, aged between 26-68, mostly female (N = 8), and mostly white (N = 7). All from inner-city London.	To explore experiences of psychosis onset and help-seeking in service users and carers.	*Recruitment* Purposive sampling of participants who had been in contact with community organisations during the FEP. *Data Collection* Semi structured interviews. *Analysis* Thematic Analysis.

Cadario et al[41]	A qualitative investigation of first-episode psychosis in adolescents.	2012 New Zealand	Carers and Individuals. 11 young people with FEP, aged between 15-18 years, and mostly male (N=7). A mix of NZ European, NZ Māori, and mixed NZ parentage. 11 primary caregivers of the same young people, mostly mothers (N = 10).	To examine experiences of FEP and accessing treatment from the perspectives of adolescents and primary caregivers.	*Recruitment* Criterion sampling of participants from mental health services. *Data Collection* Combination of structured and unstructured interviews. *Analysis* General Inductive Approach.
Anderson et al[34]	'There are too many steps before you get to where you need to be': Help-	2013 Canada	Individuals. 16 individuals diagnosed with a psychotic disorder.	To describe experiences of pathways to care in FEP and identify factors impacting on the help-	*Recruitment* Recruited from a specialist psychosis program, using

	seeking by patients with first-episode psychosis.		Aged between 20-24 years, with a median of 22.5 years. Most were male (N = 12), and born in Canada (N = 12). Participants spoke English (N = 6), French (N = 3), or were bilingual.	seeking process.	criterion sampling. *Data Collection* Combination of structured and unstructured interviews. *Analysis* Content Analysis.

Collective Methodological Critique of the Literature

Elliott et al's[43] guideline on qualitative research standards provides a comprehensive model for quality assessment (See Appendix A.4). This informed a collective methodological critique of the literature (Appendix A.5 details critique of individual papers):

Explicit scientific context and purpose, and specification of appropriate methods.

Seven studies provided comprehensive contexts and clear aims.[34,35,37–42] One had unclear aims,[36] and the rationale of a particular research aim is lacking in another.[38] All the studies employed justifiable and appropriate research methods. Detailed specification of methods increases reliability, and demonstrates the rigour of the research, which readers can appraise accordingly.

Recruitment methods.

All studies detailed their recruitment methods; four[34,38,39,41] provided especially detailed and replicable methods, and two[34,41] provided context for their recruitment strategies. All studies except one[35] provided inclusion criteria.

Data collection methods.

Two studies refined data collection methods following a pilot, which included role playing interviews.[38,42] All studies described data collection methods, but only three[34,38,39] provided a replicable level of detail. Six papers included a description of the tools used to collect data,[34,37–39,41,42] and saturation of data was confirmed in four papers.[34,36,38,40]

Analysis methods.

Two studies provided brief information on the approach to analysis,[36,42] and five studies provided a replicable level of detail.[34,38–41] This amount of detail enables readers to check interpretations, increasing credibility. Two studies

provided very little detail regarding their analysis methods,[35,37] preventing judgment on the quality of analysis undertaken.

Ethics and reflexivity.

The majority of papers did not include sufficient information regarding ethical considerations to enable assessment of ethical standards. Only three papers[35,38,41] included some consideration, while two[34,36] did not consider the impact on participants of concerning practices; paying participants,[34] and collecting unnecessary patient data.[36]

'Owning one's perspective' (p.221) involves transparency regarding the researcher's orientation and anticipations, and the potential impact of these on the research.[43] It is otherwise known as reflexivity. All but two papers[38,41] were entirely lacking in this aspect.

Situating the sample and grounding in examples.

Sufficient detail regarding participants should be presented, to allow readers to consider the relevance of findings.[43] Most studies provided demographic details of participants,[35–40,42] and some presented demographics for the person cared for.[35–38,42] Some studies linked quotations to the family role or other demographics of the person giving the quote;[36,37,39,40] this enables assessment of the degree of representativeness of quotations used. Quote linking may be omitted to preserve participant confidentiality; however this was not cited as an intention by any authors who did not link quotes.

Six studies grounded results well in examples;[36–41] two studies could have provided more qualitative examples[35,42] and two could have made clearer links between findings and examples,[40,42] to illustrate how their findings were informed by these.

Credibility checks.

Elliott et al[43] provide a number of possible credibility checks, which can increase the robustness of findings. All studies but one[35] detailed some credibility checks. These included multiple coders discussing and agreeing codes,[34,36,37,39,41,42] review of codes by an independent judge,[38–42] and returning findings to participants for validation.[38] Two studies included

measures to allow and account for cultural differences in their participants,[41,42] six studies acknowledged difficulties in transferring findings to other populations,[36,37,39–42] and four studies reflected on sample bias.[38–40,42]

Clarity of presentation, resonance and coherence.

Findings were most clear when grouped into themes.[34–36,38–41] Six papers[34,36,37,39,41,42] resonated strongly, appearing to accurately represent and expand upon the subject matter.[43] Coherence, the extent to which understanding is structured within an paper,[43] was generally good in most papers.[34–36,38–42]

Appropriate discussion and contribution to the knowledge base.

All studies considered research findings in light of the current knowledge base. Two studies[36,37] included only minimal evaluation of the limitations of their study, and this was entirely absent in one study.[35] Studies presented both clinical[34,36–40] and research[34,36,38–41] implications, based on findings. Two papers did not consider implications of the research.[35,42]

Overall quality of the literature.

On the whole, rigorous research methods were adopted, with all papers describing their methods, in varying levels of detail. Ethical considerations were less explicit, and despite its importance in qualitative research, reflexive accounts were lacking in most papers.

Pearse's[38] thesis is comprehensively reflexive, perhaps because it is longer than a published paper. This suggests that reflexivity may be absent from published papers due to space restrictions. Due to content priorities in peer reviewed journals, reflexivity may be deemed expendable by authors and editors. However, reflexivity increases rigour in both practice and reporting. It enables researchers to consider biases which may impact on their research, from study design to analysis. Reporting reflexive considerations also enables readers to judge the credibility of findings and conclusions. As such, reflexivity should be encouraged by journal editors reviewing qualitative research.

Synthesis of Findings

This synthesis describes the dominant story of help-seeking within the combined literature, examining where carer and individual experiences diverge and converge. Elucidation of less prevalent stories also demonstrates the diversity of help-seeking experiences. Informed by a guide for synthesis,[44] each paper's relevant themes were identified, then all themes were combined, synthesising findings into an integrated narrative, intended to enable deeper understanding of help-seeking experiences within the whole family.

Czuchta et al[35] describe a 'continuous help-seeking' (p. 166) process which comprises carers persuading their loved ones to seek help, help-seeking from community supports, help-seeking from professionals, and finally a crisis leading to hospitalisation. While the order of these stages is interchangeable, and the final stage may not always occur, these findings broadly reflect the journey described within the papers selected.

Initiation of Help-Seeking

"I eventually told my mum what happened."[41]

One study[41] found that one-third of the young people interviewed sought help initially from their parents. Similarly, approximately one-third of the individuals in another study sought help following a gradual process of recognising their symptoms as mental health difficulties.[39] Some individuals sought help from their doctor,[38–40] sometimes without their carers' knowledge;[38] others also had no family involvement, instead seeking help within work or school.[34]

Most often however, carers or others initiated help-seeking;[42] this is reflected in the focus of the majority of the studies.[35–38,40,42] Some individuals had no interest in seeking help, but allowed carers to do this on their behalf.[38] The extent to which help-seeking was harmonious within a family was liable to change,[38] with individuals alternately acknowledging and denying their need for help.[38,39]

Some individuals only realised they were ill once they were receiving help and information from mental health services.[39,41] This highlights the difference in perspectives between some individuals and carers when carers seek help. Experiences of frustration and disempowerment may be shared by individuals and carers during this time, while ideas about solutions may differ.

"...as far as seeking it out as an individual I likely wouldn't have."[34]

Individuals were often encouraged to seek help themselves.[39] Encouragement and pressure either aided help-seeking, or were met with anger, denial, and worries about stigma.[39,42] Some individuals felt it was important that that others sought help on their behalf.[34,41] They felt they would not have sought help alone[34] and that they got better more quickly due to their carers' interventions.[41] Some carers made a conscious decision not to seek help, seeing this as something individuals must do alone, something they were capable of doing themselves, or not wanting to infringe their autonomy.[36] However, Cadario et al[41] describe carers as advocates during difficult times for individuals, and in light of individuals' retrospective appreciation of carers' help-seeking, not doing so may delay access to services, and isolate individuals during difficult experiences.

Informal Help-Seeking

"...not knowing...where to go first."[41]

Both individuals and carers reported knowing they needed help, but not knowing where to get this from.[34,39–42] Vagueness of symptoms confused carers,[39] and they initially sought help from friends,[35,36,39–42] relatives,[38,41,42] or colleagues.[38] This was to check out concerns,[38] confirm worries,[42] or get advice,[36,42] and could result in either encouragement[42] or discouragement[39,42] to obtain formal help. Individuals sought help from their parents,[41] other family members,[39] friends[39] or partners.[39] They were usually encouraged but some experienced unhelpful responses, such as minimising

problems or criticism.[39] Friends[36,40] or family[38,41] with knowledge or experience in mental health were particularly helpful, and formal help was sought sooner if they were supportive.[36,42] The internet[36] and helplines[38,42] also served as initial contact points for carers, however individuals did not describe using these resources, possibly due to not knowing of them.

"I think she's not well...we go and see the priest"[41]

Non-mental health professionals were also approached; carers consulted educational staff,[38,41] spiritual leaders,[38,41] social workers,[38,42] and emergency department staff.[38,41] Some individuals however, were reluctant to approach such professionals for help, and where these were part of their help-seeking experience, professionals usually encouraged individuals to seek help, often making referrals to their doctor or mental health services.[39] These professionals included an employer, educational contact, hostel worker, youth worker, prison officer and counsellor.[39,41] Non-mental health professionals approached by carers may have been involved with the whole family, whereas those who encouraged individuals may have had contact with them alone. Therefore, while carers utilised the network around the family, individuals may have received support confidentially and in isolation from their family.

Two studies found that social workers helped access to psychiatric services,[40,42] while another[41] found that school teachers responded effectively. Some initial contacts led to referral to a doctor or specialist services,[39–42] while other contacts were not helpful.[41] The step of approaching a doctor may indicate a realisation of the seriousness of the difficulties faced.

Seeking Formal Help

"My daughter refused to see the doctor in spite of our efforts to arrange a consultation for her"[42]

Individuals described how hard it was for them to seek formal help, due to internalised stigma about mental illness,[34] and a tension between realising they needed help, but struggling to identify themselves as a 'sick' person.[34] Some individuals went to their doctor with physical health concerns initially, rather than asking for help with their mental health.[39]

Doctors in primary care were often contacted as the first formal attempt to get help;[38,39,41,42] however some carers contacted hospitals or mental health services directly.[41,42] Some carers felt uncomfortable discussing the situation with their doctor,[40] but it is unclear whether this was due to their relationship with the doctor, or discomfort in discussing the individual's problems on their behalf. Often, when carers sought help, efforts were impeded by the individual not recognising the need for help[38,39,42] or not accepting help,[37–39] despite attempts at persuasion.[35,39] This was at times compounded by doctors and services being unwilling to help without the individual's consent,[38] or if they did not seem unwell enough.[40] A tension between addressing carers' concerns and respecting individuals' rights is therefore apparent. Frustration was described by family members[37,38] when their efforts to seek help were hampered by the individual or services. Conversely, individuals described having little control over the help-seeking process, with referrals to specialist services being made without their knowledge or consent.[39] Without consensus within the family about help needed, it is inevitable that someone will feel dismissed and disempowered, while another is vindicated.

"we were left with him in this state"[38]

Formal help-seeking did not always immediately result in referral to specialist services.[38,39] Instead practitioners gave medication,[38,39] dismissed concerns,[34,38,39] or gave unhelpful advice.[39,40] Carers described difficulties

with appointments being inflexible,[37,38] inconsistent advice,[38] and feeling deserted.[36,38] Carers struggled to provide support,[40] and carer burden increased.[35] The uncertainty faced was described as highly distressing.[39,41] Carers appeared at the mercy of services,[36] and felt some practitioners appeared intimidating[40] or unable to engage with the individual.[40] Likewise, individuals described feeling misunderstood and dismissed by practitioners who lacked empathy,[34] and told professionals what they thought they wanted to hear, due to feeling disbelieved and judged as 'the patient'.[34] However, individuals were sometimes vague about their symptoms, or emphasised physical concerns, being reluctant to admit to their mental health difficulties.[39] This may have contributed to some of the unhelpful responses received. Such difficulties lead to some passivity in families,[38] but mainly to action, with carers contacting specialist services or other mental health professionals directly.[40]

"She referred...straight on"[41]

In contrast, some practitioners engaged individuals well,[40] were resourceful,[40] and prompt in referring to specialist services.[40–42] A good GP relationship expedited access to specialist services.[38] Wong's[42] research depicts a particularly straightforward route to receiving specialist help, which may reflect effective care pathways for psychosis.

Seeking Specialist Help

"We kept on getting sick of telling our same story to different people"[41]

When seeking help from specialist services, families reported inflexible appointment times,[36] convoluted processes,[35,36,39] and lack of communication between services,[35] which seemed 'crazy'[36,40] to those caught up in the process. Some young people were faced with entering adult mental health services, which their parents thought were unsuitable for them.[40]

Carers defined obtaining help as a long process.[35,36,39,41] One study[40] describes a process of 'door-knocking'; going from service to service to gain

access to appropriate support, and another[41] details involvement of numerous agencies. At times, services and staff did not deem individuals to be unwell enough to warrant help from specialist services.[40,42] This may have been exacerbated by carers not knowing how to negotiate support from these services.[40]

Some families struggled to access specialist help due to financial difficulties,[36,42] or difficulties attending treatment locations.[42] Even when accessing help, inadequate support[40] and lack of definitive diagnosis[37] or professional opinion[40] furthered frustrations.

"Usually people have to get really sick...some sort of crisis happens"[40]

Crises boosted help-seeking, and were often the point at which specialist help was received.[35,37,39–41] Police involvement was described,[35,37] and the subsequent response was traumatic and intrusive for the whole family.[37] Crisis support was sometimes viewed as inadequate and arriving too late.[40]

"I got good at 'playing the system'"[40]

Carers had to convince health care professionals that help was needed.[35] Driven by desperation,[38] carers resorted to begging for[38] or insisting upon[38,41] help and information. Through persistent help-seeking efforts, some carers became knowledgeable and experienced in accessing services.[40] They attended support groups and courses to gain knowledge, which increased confidence and assertiveness; families learnt how to 'play the system' and boost success in obtaining support.[40]

"Then he was put in to hospital"[40]

Once help was given, which often included hospital treatment,[34,35,37,38,41,42] carers described feeling excluded and blamed, being given little information.[38] Carers had to seek out information, finding this beneficial once received.[41] Involuntary hospitalisation was stressful[41] for carers; they described a sense of sadness,[35] betrayal[38] and guilt.[37] This was a 'traumatic

yet necessary'[37] step, which provided help for carers as well as the individual.[37] Some individuals felt they lost their control during treatment,[34,41] which caused anger for some.[34]

"I got admitted...they sorted me out from there...it was good"[41]

Other individuals described hospitalisation as a positive experience,[34,41] which included a sense of community.[34] However, implicit in almost all descriptions of hospitalisation was the notion that individuals were hospitalised against their will; individual choice was indicated only once.[34] This high incidence of involuntary hospitalisation suggests disharmony in families' experiences at this time, with intervention focused on the individual.

"...it maintained our love and support of each other"[34]

One study[35] describes disruption in the family following help-seeking. However, in another,[34] individuals detailed unexpected benefits of their help-seeking, feeling the experience brought them closer to family and friends, and strengthened existing bonds. They also felt more aware of what their family was willing to do for them, as well as the limits of what their family was able to do.

Alternative Stories

Families presented wishful, alternative stories of how their experience of help-seeking could have differed, through sharing how they or services could have responded differently.

"Just go for help straight away"[41]

An alternative story where individuals talked with others about what was happening,[34] carers sought help sooner[41] and everyone talked with one another about the difficulties[38,41] was presented. This indicates that families were aware of the division of experiences during this time, between the

individual and carers. Where individuals sought help in isolation, carers wished they had been brought in sooner and involved more by professionals.[37,40] Individuals in Anderson et al's[34] study advised others to listen to their doctor, though it is unclear whether this is something they found it easy or difficult to do at the time.

Families wanted basic responses from professionals, such as compassion,[40] listening,[38] understanding[40] taking concerns seriously,[34,38] giving advice[37] and the chance to ask questions.[37] Carers had ideas relating to how services could respond differently;[36,38] a link person would be available for the family and individual,[38] and calls would be returned.[36] Helplines would be available,[39] and services would also offer support groups and information.[41] Alternative stories about services presented by individuals related to the time when help was initially delivered, perhaps reflecting that some individuals are not active in the help-seeking process. These described a shorter wait for help, in uncrowded waiting rooms, with communication between professionals eliminating the need for stories to be continually repeated.[34] Less coercion and a shorter inpatient stay were also desirable. Individuals wished that early intervention services were more visible,[34] so that they knew there were people who could help. An alternative story relating to wider systemic differences was expressed in McCann et al's[40] study, where more funding, and services for young people existed. This underlines an overall inequity of international availability of EI services.

Conclusions

Integrating individuals' and carers' help-seeking experiences enabled each to provide context to the other, presenting a fuller account of the help-seeking experiences within families. A focus on the dominant narrative of help-seeking within the literature highlighted the difficulties faced by many; while considering less prevalent narratives demonstrated the richness and variety of experiences.

The synthesis suggests that some of the broader experiences of help-seeking are similar for individuals and carers, such as confusion about where to access help, difficulties obtaining adequate support from doctors, failed help-seeking attempts leading to a crisis point, and the importance of support from others during help-seeking. Individuals were generally less likely to initiate help-seeking, recognise the severity of their difficulties, or be as active in continual help-seeking from services, and often eventually received forced intervention. Carers on the other hand approached a number of informal contacts for advice, felt frustrated at provision of help depending upon individuals' presentation, continually sought help from services, and felt relieved but let down during crisis support.

This dominant story of help-seeking was mitigated by the less prevalent stories of help-seeking where this was harmonious within the family, doctors were responsive and helpful, and services and support were accessed quickly. This counter narrative provides hope for providing early intervention and improving help-seeking experiences for families. Such stories could inform aims for service and policy development, while lessons can be learned from the more challenging experiences presented.

Directions for the Future

The three most recent papers reviewed[34,39,41] included individuals' experiences of help-seeking. This indicates a shift in research aims to include the individual perspective, which is much needed. The findings of these studies demonstrate that individuals' perspectives are important, and can have implications for clinical and research developments.

This review represents a part of the beginning of the story of FEP for families. This provides a point of comparison for the subsequent research study, which elucidates another chapter in this story, where families are completing an intervention.

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Appendices A: Literature Review Paper Appendices

Appendix A.1: Complete List of Databases Searched

1. EBSCO Host 'life sciences' & 'All health' databases
   - Academic Search Complete
   - CINAHL Plus Full Text
   - eBook Collection (EBSCO Host)
   - MEDLINE
   - PsycINFO
   - SPORTDiscus with Full Text
   - AMED
   - Ageline
2. Web of Science
3. EMBASE
4. BNI

These databases were selected for their focus on health and life sciences. While SPORTDiscus and Ageline were less likely to return relevant results, these formed part of EBSCO's 'life sciences' and 'All health' database clusters, therefore became part of the search.

Appendix A.2: Complete List of Search Terms Used

Terms relating to first episode psychosis	Terms relating to families, service users and carers	Terms relating to experiences	Terms related to seeking help or treatment
"first episode psychos*s"	famil* NOT familiar	experience	"help seeking"
"first episode of psychos*s"	patient	pathway	"help-seeking"
"first onset of a psychotic disorder"	"service user"	journey	"treatment-seeking"
"first onset of psychos*s"	client	outcome	"treatment seeking"
"first presentation of psychos*s"	carer		"access to care"
"ultra high risk"	relative		"seeking treatment"
"first-episode psychos*s"	caregiver		"seeking help"
"first-episode-psychos*s"	care-giver		"service access"
"early schizophrenia"			"early intervention"
"early psychos*s"			"early-intervention"
"early stages of schizophrenia"			"access to services"
"early stage of schizophrenia"			"access to help"
"first episode schizophrenia"			
"first-episode schizophrenia"			
"first episode of schizophrenia"			

Appendix A.3: Model used for Quality Assessment

Elliott et al's[43(p 220)] evolving guidelines for publication of qualitative research studies in psychology and related fields.

A. Publishability Guidelines Shared by Both Qualitative and Quantitative Approaches

1. Explicit scientific context and purpose
2. Appropriate methods
3. Respect for participants
4. Specification of methods
5. Appropriate discussion
6. Clarity of presentation
7. Contribution to knowledge

B. Publishability Guidelines Especially Pertinent to Qualitative Research

1. Owning one's perspective
2. Situating the sample
3. Grounding in examples
4. Providing credibility checks
5. Coherence
6. Accomplishing general vs. specific research tasks
7. Resonating with readers

Appendix A.4: Critique of Individual Papers

Author	Strengths	Weaknesses
Pearse[38]	• Related background literature to study aims throughout introduction. • Included a section on ethical considerations, detailing informed consent and participant briefing. • Especially detailed and replicable recruitment and data collection methods, with data saturation discussed. • Reflexivity included: - presented expectations, enabling consideration of how these may affect findings. - sample of the reflexive journal was provided - power dynamics considered.	• Gender differences of those with psychosis chosen for comparison. Evidence presented regarding gender differences in attitudes to help-seeking, which suggests a comparison of experiences by gender of the help seeker would be more relevant. • Omitted consideration of the impact of recording some interviews by hand rather than audio tape - data may be less rich in these instances, leading to potential bias within the findings.

	• Grounded theory analysis of findings comprehensive and relatively complex, yet coherent and contributed to the knowledge base. • Presented an abstract theoretical framework with the intention of increasing transferability of findings.	
Czuchta et al[35]	• Ethical considerations made, including participant briefing. • Detailed recruitment process.	• No interview guide included. • No information on process of thematic analysis. • No reflection on potential bias caused by using field note observations within analysis. • No detail of credibility checks. • Minimal description of qualitative findings. • Authors referred to a future paper containing further description of qualitative findings, which has not been

		published to date. • No reflexivity or implications of the research discussed.
Wong[42]	• Adapted an existing English language interview guide to suit the cultural context of Hong Kong, further adapting questions following role played pilot interviews. • Analysis by two raters, with codes cross checked • Acknowledged potential sample bias, due to governmental privacy restrictions. • Presented a diagrammatic pathway model which summarised findings well, presenting a clear account of Chinese pathways in early psychosis, and comparing this to previous findings.	• Limited qualitative data presented; results predominantly presented as descriptive statistics, with only a small amount of quotations. • Quotations not linked well to findings. • No ethical considerations, reflexivity, or clinical implications given.
Bergner et al[36]	• Data saturation discussed. • Allowed data to convey findings, without a more abstract	• Research aims appear unclear; while expressing an interest in help-seeking experiences, the researchers then focus on aspects of DUP.

	level of analysis. This facilitated a clear and strong presentation of family members' experiences, that resonates with the reader. • Findings and discussion presented in a coherent manner. • Highlighted internal validity of their study, due to a homogeneous sample	• Collected data on the patients related to those participating in the study, via several clinical measures. It is unclear why this was necessary for the research purposes, and results were not considered in light of the qualitative findings obtained. • No reflection on the ethical implications of collecting such clinical data, which appears unnecessary.
Gerson et al[37]	• Long quotations used which despite the lack of clear themes, portrayed families' experiences clearly. • Considered findings in relation to relevant literature and policy, presenting action focused implications which may increase the utility of their research.	• Included much on experiences following treatment and diagnosis, which did not meet their research aims. • Recruitment method involved asking patients to nominate a family member who would best describe them. This is irrelevant to the research aims of gaining insight into family members' experiences, and there is no reflection on the potential sample bias within this approach.

		• Merely stated that 'established qualitative data analysis procedures' were followed, preventing judgment on the quality of analysis undertaken. • Claimed that themes were obtained, but did not delineate these within their results, instead providing an entwined narrative of findings. This masked the main themes discovered. • No reflexivity.
McCann et al[40]	• Data saturation discussed. • Themes grounded well in examples • Linked quotes to specific participants • Acknowledged potential sample bias - reflected that caregivers with less critical views may have been intentionally recruited.	• Do not explain their decision to supplement some of their quotations using comments in parenthesis; these appear to be interpretations, which may subtly alter the intended meaning of the participants' choice of words. While interpretation is applied to textual data in IPA, these supplementary comments add an extra layer of interpretation.

		• No reflexivity.
Tanskanen et al[39]	• Replicable recruitment, data collection and analysis methods. • Provided comparative demographic statistics of all users of the service where participants were recruited from, enabling assessment of the representativeness of the sample. • Analysis completed by two researchers with a third to check codes. • Generous number if quotations, linked to participant demographics. • 'Additional file' of supporting quotations made available. • Number of participants represented by each theme was detailed, , enabling clear judgement of the applicability of	• No ethical considerations or measures described. • No reflexivity.

	each theme to the sample. Exceptions to findings also discussed. • Consider limitations and generalisability. • Provided several clinical and research implications, which were well grounded in findings.	
Cadario et al[41]	• Detailed an ethical approach to their study design, including how young participants were protected. • Detailed and replicable recruitment strategy, with context for this provided. • Detailed reasons why potential participants declined participation. • Reflexively considered the positions of their researchers during analysis.	• Difficult to discern the context of quotes at times, in terms of what aspect of experience the quotations relate to.

	• Used a Māori nurse as part of the analysis team to identify Māori specific issues. • Undertook overall checks for theme consistency. • Provided a wealth of quotations to illustrate their findings, including an appendix of quotes. • Consideration of the similarities between individual and carer experiences is novel and valuable.	
Anderson et al[34]	• Replicable recruitment strategy, with context for this provided. • Replicable data collection and analysis methods.	• No reflexivity. • Did not consider the potential ethical implications of paying their participants.

	• Data saturation discussed. • Two researchers coded transcripts. • Chose not to over analyse results, as wanted to describe experiences as told. • Quotations elucidated themes well. • Authors stated how many participants expressed various sentiments within the themes, demonstrating the accuracy of their findings. • Provided service improvement recommendations which came direct from participants - high clinical utility.	

Paper 2

Empirical Research Paper

Journeys into Recovery: Family Narratives of First Episode Psychosis and Behavioural Family Therapy

Word count = 7,753

Preface to the Empirical Research Paper

Use of the term 'family'

During the design of this research, the term 'family', was used to describe any group of individuals who engaged in Behavioural Family Therapy (BFT), as BFT is delivered with family members related by blood or marriage, cohabiters, friends, neighbours or carers. However, all of the families participating in this research consisted of parents and adult children, where the child had experienced a first episode of psychosis. This enabled consideration of parent-child dynamics within the families during the interpretation and discussion of findings.

Abstract

This empirical research paper provides insight into families' shared experiences of a first episode of psychosis (FEP) and subsequent Behavioural Family Therapy (BFT). Recognition of the role of families in the development of and recovery from schizophrenia has led to recommendations for family therapy following psychosis. BFT uses psychoeducation and behavioural training, and has quantitative evidence of effectiveness. BFT, and family therapy in general, requires collaborative family engagement. Therefore, exploring shared family experiences of BFT and elucidating the process of recovery within the shared family sphere can provide insight into how BFT is effective.

Using a narrative approach, families completing BFT were interviewed, and their shared narratives were identified. These narratives reflected families' journeys from before the FEP, to the present time, via BFT, and included ideas about the future. Subplots within each family's narratives were identified, and compared across families. A broad restitution narrative of the journey from illness to recovery is presented, with subplots of the journey considered. A counter story is considered in comparison to the dominant narrative. The extent to which narratives can be evidence of effectiveness in BFT is explored, as well as considering how such narratives may aid recovery. Parental power is discussed as influencing family narratives, and the impact of BFT on this is considered. Findings may aid clinicians in their delivery of BFT, and could provide a basis for an educational resource for clinicians and families. The novel research approach may guide future research into shared narratives; further research areas are considered.

Introduction

First Episode Psychosis

First Episode Psychosis (FEP) is an ambiguous term (Breitborde, Srihari, & Woods, 2009) relating to an initial episode of psychosis. FEP and psychosis are not diagnostic terms, but describe a clinical presentation used in the diagnosis of any psychotic condition, such as schizophrenia, psychotic depression or bipolar disorder, which have substantially overlapping symptoms (Rosen et al., 2012). The prevalence of psychosis in the general population is estimated at 1% in those over 18, and 0.4% in those aged 5-18 (National Institute of Health and Care Excellence [NICE], 2013, 2014), with FEP often occurring in late adolescence or early adulthood. Positive symptoms include hallucinations, delusions, or confused thinking; and negative symptoms include withdrawal, loss of energy, interest, and motivation. Mood disturbance can also be experienced (American Psychiatric Association [APA], 2013).

Early intervention (EI) services have been developed to provide support during FEP (Department of Health [DH], 2001), with a view to preventing poor longer term outcomes. NICE (2014) posits that most people can recover from FEP with early detection and intervention. This focus on psychosis represents a shift from established ideas about schizophrenia being a lifelong condition (Berrios & Hauser, 1988), to ideas about recovery (Gumley, Braehler, Laithwaite, MacBeth, & Gilbert, 2010).

Family Therapy for Psychosis

Family intervention is recommended for psychosis (DH, 2001; International Early Psychosis Association Writing Group, 2005; NICE, 2014); this was first indicated following observations that patients living in families with high expressed emotion (EE) were more likely to relapse following discharge from hospital (Brown, Birley, & Wing, 1972; Vaughn & Leff, 1976). High EE was characterised by hostility, criticism, and emotional over-involvement (Brown

et al., 1972). Research demonstrated the benefits of psychosocial intervention, including psychoeducation (Anderson, Hogarty, & Reiss, 1980) and family intervention (Falloon & Pederson, 1985), in improving outcomes for those with schizophrenia. The initial context of family blame suggested by EE theories was mediated by an understanding that relatives may employ unhelpful strategies to cope with and manage behaviour (Mueser, 1989); today, the role of family dynamics in illness and recovery is explored from a more positive perspective.

There exists a vast amount of quantitative research into the effectiveness of family interventions for psychosis and schizophrenia (Kuipers, 2007; Pfammatter, Junghan, & Brenner, 2006), which have been demonstrated to reduce the risks of relapse (Girón et al., 2010; Pilling et al., 2002). Several studies have explored experiences of family interventions for psychosis or schizophrenia. These describe a safe therapeutic environment, connection with others through sharing experiences and difficulties, creation of new shared meanings through changed relational patterns, increased empowerment for individuals, and timing and structure of interventions as important (Allen, Burbach, & Reibstein, 2013; Nilsen, Frich, Friis, & Røssberg, 2014). An evaluation of a Family Support Service found high satisfaction levels despite initial negative preconceptions about family intervention, with families reporting improved communication, increased understanding, better coping strategies, and greater independence (Stanbridge, Burbach, Lucas, & Carter, 2003).

Both quantitative and qualitative research has demonstrated the effectiveness of family interventions for psychosis, and various interventions have been developed. This research focuses on one of these interventions; Behavioural Family Therapy.

Behavioural Family Therapy

Behavioural Family Therapy (BFT) was developed by Ian Falloon and colleagues to treat schizophrenia, and later psychosis (Falloon & Liberman, 1983; Falloon, Boyd, & McGill, 1984). They posit that families are the

greatest resource for managing stresses and maintaining a satisfying life (Falloon, 2003). Informed by a stress-vulnerability model (Zubin & Spring, 1977), BFT increases family resiliency through psychoeducation, relapse planning, promoting positive communication, developing problem solving skills and stress management (See Appendix B.1 for a standard BFT programme). Families usually participate in 10-15 sessions, which are tailored to their needs. The BFT model is championed by The Meriden Family Programme (Meriden, 2015), and is widely adopted in EI services throughout the West Midlands, but also used both nationally and internationally. However, engagement in BFT, and use of BFT by clinicians can be low, thus further research may elucidate difficulties in the clinical application of BFT (Fadden, 1997; James, Cushway, & Fadden, 2006).

A review of the literature found BFT to be effective in reducing carer burden, improving coping skills, and increasing knowledge about schizophrenia (Macleod, Elliott, & Brown, 2011). A further study found BFT to be effective in improving problem solving, reducing risk of subsequent psychotic episodes and shortening recovery times (Doane, Goldstein, Miklowitz, & Falloon, 1986). Qualitative research on families' experiences of receiving BFT described collaborative engagement and dedicated therapists as important, with aspects of the BFT being useful in reducing isolation and stress, and empowering families (Campbell, 2004).

Rationale for the Current Research

While the quantitative evidence for interventions in FEP is vast, Larsen (2007) highlights a need for increased qualitative research to provide alternative empirical evidence for interventions, arguing this will reveal how such quantitative outcomes arise. Research on experiences of FEP has focused either on individuals' experiences of FEP (Judge, Estroff, Perkins, & Penn, 2008; Thornhill, Clare, & May, 2013) or carers' experiences (Corcoran et al., 2007; Stern, Doolan, Staples, Szmukler, & Eisler, 1999), and discrete periods of the psychosis journey are often covered, such as recognising and responding to psychotic symptoms (Corcoran et al., 2007; Judge et al., 2008), or recovery (Thornhill et al., 2013). Thus, further research to advance

understanding on the full trajectory of FEP is recommended (Boydell, Stasiulis, Volpe, & Gladstone, 2010).

Paper one presented a review of the literature on family experiences of help-seeking during FEP. This identified a common journey of help-seeking; however while experiences as the result of help-seeking were similar for carers and individuals, consensus on the need for help and action to be taken generally differed. This indicates shared experiences of disempowerment and frustration, which may arise for different reasons. Therefore, family experiences during this time appear inharmonious. During BFT, families engage collaboratively to move forward positively from the FEP, and to develop resilience as a family to reduce risk of relapse. The shared family concept of the FEP, and of recovery, are therefore a vital part of this process. However, research into shared family experiences of FEP appears to be lacking. This research aims to contribute to the evidence base for family interventions, with a focus on process rather than quantitative outcomes, and an exploration of families' journeys, from pre-morbidity to ideas about the future, via BFT.

Aims

- To explore the collective story told by families, when one member has experienced FEP and the family undertakes BFT.
- To consider the extent to which narratives can be used as evidence of effective BFT, where effectiveness is idiosyncratic to each family's hopes and aims for intervention.

Method

Narrative Research

Narrative approaches are based on the assumption that people understand and interpret their world through stories (Bruner, 1990). Rappaport (1995, 2000) defines stories as sequenced events with a beginning, middle, and end, that have a point, which help us find meaning in our lives. Stories may not present unequivocal truths, but represent a narrator's version of the sense they have made of a phenomenon (Frank, 2012). Stories both describe past experience and enable individuals to make sense of this (Riessman, 2008), therefore interpretation of narratives can demonstrate how tellers have made sense of their past.

However, stories are not created in a vacuum; they are shaped by and contain broader narratives, and in turn influence these narratives themselves. Rappaport (1995) suggests that stories are an individual's unique representation of events, whereas narratives represent wider stories which are less idiosyncratic. In addition to personal stories, he distinguishes two further levels of narrative: community and cultural narratives. Community narratives are those which are shared within various groups, through social interaction and communication. Dominant cultural narratives are 'overlearned stories' (p. 803) which reach most people within a culture, through media and social institutions. These provide the cultural context within which community and personal narratives develop. Narrative research can explore the interaction between these levels, enabling consideration of the context of narratives, how and why they are created, what they describe, and how this affects identity and change.

This research intended to reveal shared family narratives, therefore a focus on collective 'community level' family narratives was maintained. Language enables the sharing and creation of both individual and collective understandings, through integrating others' perspectives into our own understandings (Fivush, 2011). Our interpretations of an event, when shared with others, develop into shared understandings through input from listeners who confirm, negate, or negotiate our stories (Fivush, 2008). Meaning arises

from collective contributions and overlapping individual stories (Seaton, 2008). As such, group interviews are distinct narrative environments, where broader narratives are created from the shared stories of participants (Gubrium & Holstein, 2012).

Recruitment

Families were recruited from three EI teams. The clinicians in these teams who delivered BFT gave those families who met inclusion criteria an invitation letter (See Appendix B.2). If families wished to know more about the research, they told their clinician, who then gave them a participant information sheet (See Appendix B.3), and arranged for the researcher to make contact. Informed consent (See Appendix B.4) was obtained immediately prior to interview. See Appendix B.5 for an overview of the recruitment process.

Inclusion criteria.

- Families with a member who had experienced FEP, and who were undertaking BFT, or had completed this within the past six months.
- Families comprised of the individual who experienced FEP, and at least one other family member.
- Families deemed able to manage talking about their experiences.

Exclusion criteria.

- Families where the individual who experienced FEP did not participate in the BFT.
- Families unable to speak fluent English.
- Those under the age of 12, or those under the age of 16 who did not have parental consent or whose carer was not participating themselves.

Ethical approval.

Full ethical approval was obtained from an NHS Research Ethics Committee, and permission was obtained to recruit from the NHS trusts involved (See Main Appendices C.2-C.5).

Participants

Four families participated in the study. These all consisted of at least one parent and one adult child who had experienced FEP. All participants were aged over 18, and of white ethnic origin. Table 1. details participant demographics, with pseudonyms used.

Procedure

Interviews were conducted with each family as a whole, at their home, where they also completed the BFT. Local trust lone working procedures were adhered to. Interviews lasted 60 minutes on average and were audio recorded. An unstructured interview approach was used, with a broad interview guide (see Appendix B.6) to encourage families to share their story.

Table 1. Participant pseudonyms and demographics

	Number of BFT sessions completed	BFT completed?	Pseudonym	Role in family	Gender
Family 1	10	No, 2 sessions remaining	Gayle	Daughter (Had FEP)	Female
			Susan	Mother	Female
			Clare	Mother	Female
Family 2	16	No, 1 session remaining	Mark	Son (Had FEP)	Male
			Alison	Mother	Female
Family 3	10	Yes, 1 week prior to interview	Dave	Son (Had FEP & has schizophrenia diagnosis)	Male
			Tony	Father	Male
			Kirsty	Mother	Female
Family 4	10	No, more sessions remaining	Gemma	Daughter (Had FEP & has bipolar disorder diagnosis)	Female
			Helen	Mother	Female

Analysis Process

An experience-centred approach to narrative analysis was adopted (Patterson, 2013), using Rappaport's (1995) model to identify different levels of narrative, and identifying experiential themes within the 'community level' family narratives.

Interviews were transcribed, then core stories were derived from the transcripts, guided by Emden's (1998) approach (See Appendix B.7). Transcripts were naively read several times, and initial impressions of the whole narrative were noted. Interviewer questions and comments, and all words superfluous to the meaning of each sentence, such as 'you know', and 'erm' were then deleted. Departing from Emden, utterances which demonstrated interaction between family members were retained, as while these were superfluous, they indicated collaborative responses, revealing family narratives. In an additional stage, fragments describing different phases of the journey within families' narratives were identified and grouped together in chronological order to highlight aspects of the past, present, and future within the narrative (Clandinin & Connelly, 2000). This 'restorying' approach enables key aspects of the story to emerge, and emphasises the context of the story (Ollerenshaw & Creswell, 2002). Throughout this restorying, content was checked against the original transcription to ensure that it retained its proper context as provided during the interview. Some aspects of families' journeys spanned all phases and were retained rather than split across different phases, to preserve their context; these were labelled 'broad aspects' of the journey.

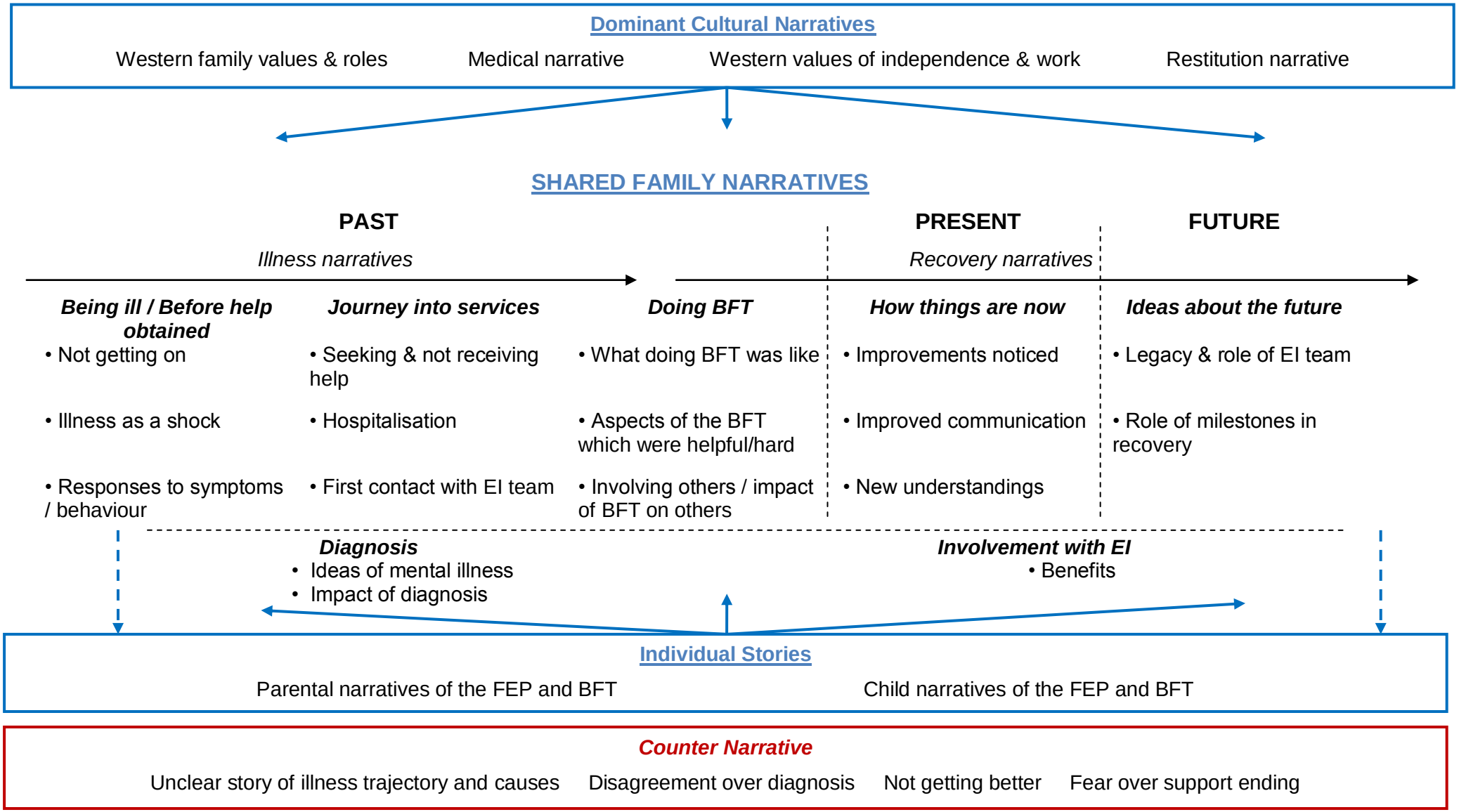
Within each phase or aspect of the narrative, fragments of themes were identified and grouped together to produce subplots of families' narratives. Shared family narratives were identified in subplots which incorporated a collective understanding or an integration of perspectives (Fivush, 2011). Some of these were expressed by a main speaker, with agreement, contribution and encouragement from other family members through nodding, chipping in, or agreeing, and which incorporated others' perspectives. Other family narratives were identified through the sharing of

family members' personal stories around a shared subject, creating a wider family narrative of the subject. Instead of returning core stories to respondents, as Emden did, subplots were considered against the initial impressions noted, to judge how trustworthy they were in elucidating families' stories. Finally, the subplots and their themes were compared across families, to identify similarities and differences. See Appendix B.8 for an example of the analysis process. The analysis approach and findings were verified by a researcher who has substantial experience in conducting narrative research.

Findings

Families' overall narratives describe the journey from illness to recovery, representing a restitution narrative (Frank, 1995). Kirkpatrick's (2008) framework for understanding stories is used as a basis to present findings, as this incorporates levels of narrative and temporality. Figure 1. demonstrates how dominant cultural narratives and individual stories impacted on the shared family narratives, and how family narratives also impacted on individual stories. Subplots for each temporal phase or broad aspect of families' experiences are shown. The majority of these focused on the past, incorporating illness narratives and the shift towards recovery narratives. Past experiences are contrasted with those within the present, and the past is interpreted and narrated through the context of families' present situation, and their journey towards recovery. This journey continues on to the future. In contrast, one family often describes a counter narrative (Holloway & Freshwater, 2007) to the dominant narrative of recovery. Theirs is a journey of continuing struggles, with a present feeling of being stuck, and fear for the future.

Figure 1. Narratives of the journey from illness to recovery (based on Kirkpatrick, 2008)



Subplots which highlight the narrative of families' experiences are described within each broad phase or aspect of families' journeys, along with aspects of the contrasting counter narrative. See Appendix B.9 for all main subplots and themes identified, and Appendix B.10 for the subplots and themes identified for each family. Findings are linked to the families they describe through inclusion of the family number in superscript.

Past Phase: Being Ill / Before Help Obtained

When narrating this time, families described difficulties within the family,[1,2] or described the FEP.[1,3,4]

Subplot: Not getting on.

A family narrative of how the family previously didn't get on emerged for two families. This involved poor communication,[1] blame,[2] and arguments[1,2] These narratives were presented in the context of how things were for the family now, with a new understanding of other's perspectives during this time.[1,2] Family 2 explained:

> *Alison: "There was a time where none of us got on with each other, it was really tense. It isn't like that anymore is it? [Mark: No]...I think Mark used to think that we were always on his back. Cus before I'd be the prime person for shouting and bawling at the top of the stairs and not getting the response I wanted, and then shouting and bawling even more, which would make you angry wouldn't it? And then Mark'd get all frustrated and we wouldn't get anywhere. Whereas now it's very different."*

This describes how the family didn't get on before, but links this to the present, with comments about how things are now different. The reflection on unhelpful patterns of communication was made within the context of a family who have completed BFT, with consideration of how others felt, and how this led to 'not getting anywhere'.

Subplot: Illness as a shock.

Rather than describing family dynamics during this phase, two families focused on their experience of the FEP, and of subsequent episodes. While family 3 presented only individual accounts of this period which focused on symptoms, suggesting a lack of a shared narrative of this time, family 4 emphasised that there were no difficulties within the family before help was obtained, describing a shared shock at the illness: *Helen: "Before Gemma was ill, there was nothing wrong!"*, *Gemma: "We never expected that it would happen, both times."* Family 4 went on to describe how Gemma raised concerns with her mom, who misattributed her difficulties to teenage problems, and only started to consider something was wrong when Gemma's symptoms worsened. The family now understood this time in the context of neither of them expecting Gemma to have mental health difficulties.

Past Phase: The Journey into Services

Subplot: Seeking and not receiving help.

During help-seeking some families were dismissed by doctors,[(2)] or made to wait long periods for referrals.[(3)] Family 3 described a turning point when they began receiving support: *Tony: "We went from 'we don't care about you, go away for 6 weeks', to 'we can do everything for you.'"* In contrast, family 4 found they were able to see the 'right people' easily.

Subplot: Hospitalisation.

Families described hospitalisation as a result of acute symptoms.[(1,2,4)] This period was described as scary and horrendous,[(1)] traumatic,[(2)] and as ruining their lives.[(4)] All families described the individual as poorly and ill, indicating the influence of a medical narrative on their present family narratives. Often the story of the illness and hospitalisation was shared by parents. Family 2 explained that it was difficult for Mark to talk about this time, and family 1 discussed how Gayle couldn't remember this well: *Susan: "We got to the hospital with the police escort..."*, *Gayle: "I don't remember"*, *Susan: "No, you wouldn't remember any of that Gayle because you were not with us really."*

Broad Aspect: Diagnosis

The individuals within two families had received diagnoses of schizophrenia[3] and bipolar disorder.[4] However, their experiences of having a diagnosis and the degree of shared family narratives around this differed.

Subplots: Suspicions of bipolar / "What if" narrative.

Family 4 described how they were both concerned that Gemma had bipolar disorder, but that this was not diagnosed until a second episode. This caused them both to wonder what might have happened had she been diagnosed sooner: *Helen: "It still makes me think, 'what if?' If she was on the wrong medication, and if she'd have had a different medication, would it have prevented that happening?"*

Subplot: Impact of diagnosis.

Family 4 described how having a diagnosis was beneficial for them: *Gemma: "It's nice to know that it is bipolar, it is something. And also it's nice to have the diagnosis to be put on the right tablets, which is good".* In contrast, family 3 described difficulties with Dave's diagnosis, feeling that any difficulties he had were attributed to this, without the problem being resolved.

Contrasting subplot: Disagreement over medication & diagnosis.

In family 3, the family explained that Dave didn't like taking his medication, whereas other families agreed on the benefits of medication. Disagreements between Dave and his doctors, and Dave and his family about his medication, were reflected in dissenting personal narratives: *Tony: "He doesn't always agree with everything. He's the one taking the tablets, he doesn't always see what position he's in himself and he can't always see the point in it...And we know it's a disaster to stop taking them."* The wider medical narrative reflected here casts Dave's stance as wrong, and potentially disastrous. At other times, family 3 challenged the narrative of schizophrenia and the impact of this label on Dave's treatment. This

challenge is not a collective one however; while Dave questioned his diagnosis of a mental illness in general, feeling he had physical problems, his father believed Dave had Chronic Fatigue Syndrome.

Past Phase: Doing BFT

Subplot: Aspects of the BFT.

Families described helpful aspects of the BFT. Some families[1,2] found the initial psychoeducation very helpful, as family 1 explained:

> *Susan: "The first most important thing was describing what psychosis was, for all of us. None of us had got any idea what it was, or why it had happened, and for us to talk about that and hear about it as a family for me was really important, that was a good start [Clare: yea] for us to move on."*

In contrast, family 4 described this initial stage as upsetting, while also recognising the benefits: *Helen: "We both said after that, that was quite depressing wasn't it [Gemma: yea] cus it was upsetting. You think you've moved on and you have to go back and talk about it again, it was, depressing."*

Families gave examples of specific exercises they had found helpful. These included psychoeducation,[1,2] communication skills,[1] making a positive request,[1] drawing a timeline,[2] identifying triggers and early warning signs,[2,4] setting up a family meeting,[3] and practising eye contact.[3] Family 4 described how they did not spend too much time on some exercises, as they already did some things naturally: *Helen: "Emma said on communication, problem solving, that we hadn't really got a problem with that, because she said we do it naturally."* Family 4's narrative that nothing was wrong for them as a family before the FEP is here supported by the treatment narrative, as shared by their clinician. While still working on these areas, this was tailored to suit family 4's needs, in line with the BFT approach. The benefits of such tailoring are reflected in comments by family 1 that the parts of BFT they found less helpful were about things they did already.

Other aspects of the BFT which families described as helpful were having an equal focus on all family members,[4] having sheets and

handouts,[2,3,4] having privacy,[1] and having a mediator which encouraged honesty and gave a different perspective.[2] Some families acknowledged the difficulty of aspects of the BFT, describing it as hard and awkward, while recognising the benefits of this.[1,4]

The exercises and process of BFT enabled a greater understanding of the FEP for some families,[1,2] as highlighted in family 2's experience of doing a timeline:

> *Alison: "Mark was very open about when the symptoms started and how he was feeling at the time and what he was experiencing, cus up until then, I hadn't got any idea that it had happened that much further back, cus it went on for a long time before we even noticed, so that was a really big turning point and for me, it was when I started, not accepting, but having an understanding of why Mark was behaving the way he was and why he did some of the things he did."*

These also encouraged a sharing of responsibility for the FEP and for recovery:[1,2,4]

> *Susan: "It wasn't just Gayle, that was the thing that was important, we all had to look at the things that we were saying, about Gayle...not only things are not right, but they're not right with any of us in a way."* (Family 1)

Subplot: Involving others / Impact on others.

Some families described logistical difficulties with arranging for some family members to attend BFT.[1,2] Despite this, family members who didn't attend BFT also benefitted from the family's learning.[1,2] Family 2 describe how this happened for them with Mark's sister, Lisa:

> *Alison: "Because of the sessions and the fact that the three of us have been able to talk more openly, Lisa has been there, like at teatime, when we've been talking more openly, so it's benefited Lisa, because she's now got a much better understanding of what Mark went through and what he experienced, and what let up to him being so poorly, and I think that's been really good for Lisa to see."*

Contrasting subplot: More helpful for parents.

While agreeing on a few helpful aspects of the BFT, an important individual narrative in family 3 was Dave's disappointment with the BFT, feeling his parents got more out of it than him, and reporting confusion over the dual

role of his nurse. This individual narrative formed part of a family narrative of Dave's parents needing support, due to Dave being unwell and needing management.

Broad Aspect: Involvement with the EI Team

Subplot: Benefit of EI team.

Some families described benefits of being involved with the EI team. These included access to social activities[1,3,4] and being helped to access work:[1,4]

> *Gemma: "I've met my closest friends at the minute through that, so that was nice...I pretty much got my job through EI as well didn't I? [Helen: yea] I'm about to start an apprenticeship, so I got that through them."* (Family 4).

Good relationships with clinicians were also described as important,[1,2,3,4] with clinicians increasing motivation for engagement,[2] going over and above what families expected,[1] providing someone to talk to,[1,2,3,4] and providing continuity of care, as family 3 explained:

> *Tony: "The worst thing, in our position is having to re-explain yourself, even Dave says this. You get fed up of saying the same things. But if you know somebody knows you, you just say 'he's been better than last time', and that's good enough."*

Present Phase: How Things are Now

Subplots: New understandings & Better communication.

Families described relating back to what they had learned during BFT.[1,3,4] Two families[1,2] described a better understanding of one another, and better communication. Family 2 explained that for them, this came from the BFT: *Alison: "If Mark does something that I don't particularly like and vice versa, we can now tell each other without flying off the handle, whereas there was a lot of that before. That's come from the family therapy..."* Through sharing the changes they had noticed, and realising different family members noticed different changes, family 1 reflected on this: *Clare: "I think a lot of the behavioural therapy has now become a way of life [Gayle: yea] [Susan: mm].*

I'm not noticing it the same." Family 4 felt these aspects were never a problem for them, but described the understanding which diagnosis provided for them.

Some families reported that relationships within the family improved following BFT, with individuals becoming more a part of the family:[1,2]

> *Alison: "We now get the sense that Mark wants to be part of the family again."*
>
> *Mark: "I'm not so much on the outside anymore, I'm more on the inner circle again, instead of sitting on the sidelines watching. Getting involved in conversations, and making jokes, and asking for things properly and, not losing my temper so much."* (Family 2)

Subplot: Noticing improvements.

Family 4, who had not described difficult family relationships previous to the FEP, instead reported the signs that Gemma was improving, such as her going out more, and being able to notice and explain her feelings within the context of her diagnosis. The family also felt more confident in identifying and responding to warning signs. Similarly, family 1 described Gayle's increased independence and progression in work as signs that she was recovering, and family 3 described Mark's taking a walk occasionally as a step towards his recovery.

Contrasting subplots: Not getting better.

In contrast to other families' present situations and steps towards recovery, family 3 described a narrative of Dave not getting better, with him being stuck, lacking independence, and feeling frustrated: *Tony: "It's ruining his life cus he hasn't got a life, have you?", Dave: "Not at times, no.", Tony: "He hasn't got a life outside his bedroom. This is as far as he gets on his own. He's stuck."* This lack of improvement was accompanied by a lack of collective understanding within the family, which contrasts with other families' improvement in this area. This was something Dave had hoped for:

> *Dave: "I thought it would help my parents understand more about what's wrong with me than it has, but they find it difficult to*

> *understand. That's why I did it. But I still end up having to explain myself a lot."*

This personal narrative shared by Dave reflects his family's more disjointed family narrative, which often wasn't created collectively, instead containing discordant individual narratives.

Future Phase

Subplot: Legacy & role of EI team.

Two families[1,2] were relatively early into their three years of support from their EI team, having over a year left. For these families, the EI teams were given a place in the families' future, whether this was through their legacy,[1] or continued support:[2]

> *Clare: "They've probably given us a toolkit of things that we can use, and ways of recognising if things are perhaps going a little bit wrong. We won't be left to drift at the end of two years, we'll be fully equipped to hopefully prevent something else from happening."* (Family 1)

Two other families,[3,4] who had less than a year of EI support left, considered this loss of support. Family 3 described a fear of Dave going backwards, and were seeking further help once they finished with the EI team: *Tony: "He'll end up going back in his box and start living in a world of your own and then you'll end up in a hospital bed again.", Kirsty: "We're in a hurry now, cus it's ending, the early intervention."* Despite family 3 being further along in their three years of EI, they described less progress and hope for the future than the other families. Contrastingly, while family 4 shared a worry of having less support if Gemma became ill in the future, this was balanced with the need to move on, and a reflection of the loss in general:

> *Gemma: "It is a worry isn't it that if something happens, they're not just on the end of the phone [Helen: yea, definitely], you can't just ring somebody. But in a way it's good, cus it's, moving on again. Got to do it some time."*

Gemma also described her apprenticeship as step on from the EI team, and a legacy of the team's support.

Subplot: Role of milestones in recovery.

Some of those who had experienced FEP were optimistic,[1,2] but found it difficult to say how they saw their future. Families often spoke about the future in terms of milestones, such as securing or progressing in work,[1,2,4] learning to drive,[2] and entering relationships.[2] These achievements were described as indicating further recovery, and perhaps because they were seen this way, rather than as factors to aid recovery, the importance of such steps happening at the individual's pace with no pressure was shared:

> *Alison: " I think me and his dad are quite respectful, and understand that that needs to happen at Mark's pace. Mark will do things when Mark's ready, and we know that if he says he doesn't want to do something, then it's genuinely because he doesn't feel that he can rather than he's just, 'I don't wanna do it'."* (Family 2)

This reflects a dominant cultural narrative of the importance of achievements such as work, and of these being significant for recovery. Mark's mother recognises the power of parents to pressurise their children, and highlights the importance of developments happening at Mark's pace. This attempt to empower Mark is underlined by a trust that he will decide what he is and isn't ready for, and can be contrasted with the narratives of blame and misunderstanding at the beginning of many families' journeys. Such a contrast demonstrates how new present understandings can have a positive impact on the future.

Discussion

The process and outcomes of BFT described by most families were similar to those described in other qualitative studies (Allen et al., 2013; Campbell, 2004; Nilsen et al., 2014; Stanbridge et al., 2003). Outcomes included improved communication, increased understanding of the FEP and of each other, greater independence, and hope for the future. However, these outcomes are explored in the wider context of families' journeys through FEP, enabling consideration of the relationship between past, present, and future experiences, and how BFT affects these. Findings also enable consideration of how the process of families' journeys towards recovery via BFT can be revealed in narratives. Exploration of shared family narratives in this way thus builds on previous research in this area.

Variation in the Narratives

Family 3 described a different journey to other families. The son of this family had received a diagnosis of schizophrenia several years after his FEP; however they had only recently completed BFT and were approaching the end of their three-year involvement with their EI service. They did not share a narrative of recovery, unlike the other families. Within the context of their delayed receipt of EI services, this supports evidence that delayed intervention reduces recovery prospects (The Schizophrenia Commission, 2012). Despite some similarities between family 3 and family 4, in the fact of there being a diagnosis, and the imminent ending of EI services, family 4's narrative is more closely aligned with those of families 1 and 2.

Narratives as Evidence

This study aimed to consider the extent to which narratives could be used as evidence of effective BFT. Narratives were not collected prior to the BFT, to enable comparison; however some families' reporting of increased understanding and improved communication was supported by the presence

of collaboratively created, shared family narratives within the interview. Shared understanding emerges from a sharing of perspectives (Fivush, 2008), which the BFT may have facilitated.

Most families described positive outcomes of the BFT, with hope for the future. The content of such narratives therefore provides qualitative evidence of the effectiveness of BFT for these families. In addition to this content as evidence, evidence of collaborative shared narratives being created by these families implies a shared and collective family understanding of the past, present, and future, which could be attributed to the BFT in the context of families' positive feedback.

In contrast to the other families' high levels of shared narrative, family 3's narrative was comprised largely of disconnected individual narratives, which did not include others' perspectives, and were often conflicting. Where family narratives existed, these were less collaborative, and were dominated by a parental narrative. This family did not report improved outcomes - while describing some useful aspects of the BFT, there was disagreement about this within the family, and they retained an illness narrative, rather than approaching recovery. Despite the small sample size, the contrast between the effectiveness as reported by most families and family 3, combined with the difference in the extent to which the narratives were collaboratively created, suggests that shared family understandings are either indicative of, or instructive in achieving, successful outcomes in BFT.

Family 4 claimed there was nothing wrong within the family before the FEP they experienced, and their clinician had judged that they did not struggle with communication and problem solving as a family, with exercises on improving communication and problem solving only minimally delivered. Family 4 had a strong shared family narrative of their experience; it appears that they had shared meanings and good communication prior to the BFT, unlike the other families. This suggests that shared family narratives are an asset to recovery following FEP, as these facilitate shared understandings and goals for recovery, which can be supported by EI teams. Most families described the support to access work opportunities and social activities as being very helpful for recovery, and this may have been a bigger factor in family 4's recovery, as there was less need for support in some of the areas

which BFT addresses. The effectiveness of BFT may therefore be observed in the extent to which it enables the evolution of shared understandings and goals through shared family narratives.

Parental Power and its Influence on Family Narratives

Rappaport (1995) describes the reciprocal influence each level of narrative has on each other; this model can be used to understand how narratives changed during BFT. Community level narratives are dominant over individual narratives; therefore family narratives will affect the individual narratives of those within the family. What community narratives exist depends on the power of the individuals within that community. Those who have more culturally defined power have more influence over the community narrative. The dominant cultural narrative casts parents as more powerful than their children, therefore parental narratives can dominate family narratives, in turn influencing their children's individual narratives and sense of identity. Where parental narratives are critical of or hostile towards a child experiencing FEP, these are likely to maintain their isolation, defensiveness, and symptoms. This can be understood within the theory of expressed emotion (Brown et al., 1972; Vaughn & Leff, 1976).

The mediating effect of the BFT clinician as an outside and neutral observer can empower children to share their subordinate individual narratives, which can then impact shared family narratives. Allen et al. (2013) similarly found that containment provided by the therapist creates a safe space for families to share their perspectives. BFT facilitates the exploration of each family member's personal narratives about the family's difficulties, and also introduces new narratives, such as medical narratives of illness, and cultural narratives regarding family roles. This shared exploration enables new, collaborative family narratives to develop, which are created through shared understanding and increased respect for others' positions, empowering the contribution of all family members to the shared narrative. Allen et al. (2013) also found that new family patterns of communication and empowerment enabled new shared meanings to develop. Increasing the

coherence of family narratives increases families' resilience (Walsh, 1996), thus preventing future relapse.

Changed family narratives impacted parents' personal narratives also. In their position of power, parents assigned responsibility to their children for their difficulties before help was obtained. This led to blame, arguments, and communication problems preventing family members understanding one another, and prevented help being sought sooner. However, some parents stated that BFT helped them accept shared of responsibility for the family's difficulties. This is also evident in how they narrated the time before help was obtained; in the context of having completed BFT, these parents noticed their role in maintaining unhelpful patterns of frustration and arguments. At the time of interview, parents recognised the value of them being involved in the BFT, and their role in their child's recovery.

Parental power was also reflected in the interview context, where parents spoke more than their children, likely feeling more empowered within the novel interview environment. However, rather than expressing personal narratives of their own experiences, with the exception of family 3, parents acted as 'spokespersons' for their family, revealing the family's shared narratives. Parents incorporated the perspectives of others into their responses, spoke tentatively and invited contributions from others. These actions suggest they were vocalising the family's shared ideas and understandings, and respected these as such by inviting contribution and challenge. This suggests that collaborative shared family narratives make parents good advocates for their children. Such advocacy is especially important when people are struggling to engage with services (Cadario et al., 2012).

Increased collective family narratives about the difficulties caused by FEP may therefore be a result of effective BFT. New family narratives will impact on individual narratives, and parental power means that changed parental narratives may be an important factor in encouraging and maintaining recovery. The importance of changing parental narratives echoes the assumptions that ultimately led to the development of BFT; those of parental responses being integral to maintaining recovery (Brown et al.,

1972; Vaughn & Leff, 1976). This idea itself is now a dominant narrative in interventions for psychosis and schizophrenia.

The Creation of Family Narratives

The children generally spoke less than their parents during the interviews. This indicates the importance of a shared family narrative, as without this, the child's narrative may be dominated by that of their parents. Shared family narratives may be particularly important for individuals to understand times where their own narrative is unclear, due to gaps in memory or a traumatic experience. When narrating traumatic experiences, individual narratives are often muddled (Seaton, 2008), therefore such accounts may be enriched by a more collective narrative. This occurred for some families, with the parents in families 1 and 2 narrating the time of hospitalisation, while their child struggled to remember or talk about this. The children in these families accepted their parents' versions of this time, implying a trust in their contribution to the overall family narrative. In contrast, family 3 were unable to agree whether or not Dave has gone to hospital during one of his episodes, and this part of the story was not resolved during the interview. This demonstrates how a discordant family narrative may contribute to families feeling 'stuck' in their understanding of, and recovery from an illness.

Parents' narration of parts of the journey which were inaccessible to their children, and their power to narrate parts their children struggled to, enabled a richer narrative to emerge. This is a strength of collecting shared narratives. For example, parents often noticed positive change that their children did not, or had hopes for the future which their children were not confident in vocalising.

Conclusions

Collaborative family narratives were present for families who also reported improvements following BFT, while the family who reported less progress had less shared family narratives, and more conflicting individual narratives. Shared family narratives emerge from an understanding and incorporation of others' perspectives, and agreement and co-construction of meaning. BFT aims to improve communication and understanding through psychoeducation and skills training, amongst other aims, therefore the presence of shared family narratives may indicate success in achieving these aims. Considerations regarding reflexivity and limitations are presented in paper 3.

Clinical Implications

This research has provided an insight into families' journeys through FEP and BFT. These illuminate helpful and unhelpful elements of BFT and of EI services, which can aid clinicians in improving their delivery of BFT, and inform the delivery of EI services. The value placed on increased understanding and improved communication, and the reflection of this in the shared family narratives, suggests that increasing collaboration in families may aid recovery and relapse prevention, and provides support for the BFT model. This is further emphasised by evidence of discordant family narratives within the family reporting less progress.

If a child is disempowered through dominant parental narratives, improvement appears unlikely. A short term measure of the effectiveness of BFT could assess changes in family communication and shared understandings; the Revised Family Communication Patterns Scale (Ritchie & Fitzpatrick, 1990) may be suitable for such purposes. If shared understandings are not present, further work on family communication may be indicated.

The narratives obtained could inform an educational resource for families, such as those entering EI services or considering BFT. This may help families to prepare for their own journey through FEP and BFT, through

relating to other families' stories. It may also help families to consider how BFT may be useful for them. The narratives could also inform a training resource for BFT clinicians, through helping them to consider how shared understanding may develop over the course of BFT, and through encouragement to return to the aims of increasing shared family understandings and communication if families appear 'stuck'.

Research Implications

This research adopted a novel approach to exploring families' experiences of FEP and BFT, through exploring collective narratives within families. This approach to narrative research is only just developing (C. Squire, personal communication, February 2, 2015), therefore the method employed may provide guidance and inspiration for other narrative researchers.

This study explored families' journeys through FEP and BFT, within the context of families who were undertaking or had completed BFT. Some families described poorer understanding of one another and poorer communication before help was obtained, and improvements in these areas are reflected in the presence of their shared family narratives. Furthermore, paper one's literature review findings suggest that family narratives may be less harmonious during help-seeking, and family 3's narrative suggests discordant family narratives may reflect continuing difficulties. Collecting the narratives of families prior to BFT would enable exploration of the extent to which family narratives are shared at this stage, and could indicate the usefulness of a qualitative outcome measure of shared family narratives.

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Appendices B: Empirical Research Paper Appendices

Appendix B.1: Outline of BFT Programme

INTRODUCTION

Overview

This workbook describes the principles and techniques of a psycho educational approach to family work known as Behavioural Family Therapy (BFT). This was developed by Professor Ian Falloon, and has been well documented. It is the type of approach recommended in the NICE Guidelines for the Management of Psychosis which should be offered to 100% of families.

This behavioural model of family work aims to enhance the efficiency of problem solving in a family unit or household. It is assumed that at any point in time, each family member is doing his or her very best to reduce the unpleasant stresses and maximise their positive feelings of well-being. Distress occurs when factors limit the effectiveness of this coping process so that stresses remain unresolved and/or positive feelings cannot be generated. The family, or it's equivalent care group of close confiding friends are the greatest natural resource in assisting an individual in coping with life stresses and in generating mutual positive feelings. However, in order to harness this resource, it is essential that clear communication of both pleasant and difficult feelings occurs between all family members, and that a clearly structured approach to resolving problems and planning and achieving goal is employed. The model of family work, outlined in this workbook assists families to seek more efficient problem solving and goal achievement by strengthening their assets and giving them the opportunity to gain new skills.

The model attempts to provide families with relevant information, strategies and skills which aim to enhance their ability to cope with their everyday stresses. It is argued that the most effective way to change mutual feelings and attitudes is through generating mutually pleasing behaviour and resolving mutual problems.

This approach has been employed widely and successfully within the fields of marital distress and parenting difficulties with children and adolescents. Within the area of mental health, studies also suggest that it is effective when working with families who have experience of psychosis, depression, anxiety, agoraphobia, Alzheimer's disease, learning difficulties and alcoholism. The evidence base in relation to schizophrenia and other psychoses in particular is very strong. Numerous reviews of the value of psycho educational family approaches in general are available (see reference list, pages 113 – 115).

Stress, Coping and Problem Solving

Many of these conditions are associated with persistent family stress. Indeed, any major disorder that has a tendency toward recurring episodes or persistent disability will severely tax the coping resources of the majority of families. This, any approach that can reliably enhance the problem solving efficiency of the family is likely to reduce stress and improve quality of life. Some disorders, such as schizophrenia or

depression appear extremely sensitive to environmental stress. Effective stress management may be an essential component in the recovery process, as well as in reducing the vulnerability to future episodes, while assisting in the service user's psychosocial rehabilitation. Research evidence suggests that the benefits of Behavioural Family Therapy in the management of mental health difficulties are associated with the lasting increases in family problem solving efficiency.

Provision of Information

One component of this model is the provision of education/information about the service users condition and experiences. The clear explanation of the physiological and social aspects of anxiety, the disturbed thought and behavioural patterns of depression, or the manner in which giving in to rituals increases the likelihood of recurrent obsessional thoughts has become a key aspect of management of those conditions. Similarly, research indicates that the educational component may play a vital part in the clinical efficacy of family work in relation to schizophrenia.

Behavioural Assessment of Family Systems

Finally, it is important to realise that Behavioural Family Therapy is a highly flexible approach. The initial assessment of the family unit seeks to pinpoint the strengths and challenges faced by each family member, their individual and collective goals and issues they face. Whenever possible, the therapist attempts to build in the strengths of the family to overcome any important deficits. The progress of working together is closely monitored on a session-by-session basis with periodic major reviews. This assessment process continues throughout the contact with the family. The direction of therapy is readily changed in agreement with family members. The essence of the approach is that it is collaborative throughout.

Summary

In summary, Behavioural Family Therapy is a powerful method to harness the resources of a family unit for the mutual benefit of its individual members. Its major focus is upon enhancing the efficiency of family problem-solving functions, including those communication skills that are vital prerequisites to effective problem solving discussion. Other components of the approach include the sharing of information, as well as a range of specific behavioural strategies that can be applied to address specific problem issues. The cornerstone of the approach is careful and continuous assessment and flexibility to meet the family's changing needs.

OVERVIEW OF THE PROCESS OF FAMILY WORK

Those new to this approach often enquire about the order in which the various components are introduced to the family. Because this is a behavioural approach, it is not possible to be rigid about the sequence in which the different skills are introduced to families. Behavioural approaches by nature are responsive to the particular needs of the individual or family and characterised by a thorough assessment which determines the content of the intervention. There are some general principles: assessment usually takes place before intervention begins; information about the relevant disorder is provided early on in meetings with the family; simple skills are introduced before complex skills; skills with a positive focus are taught before those where the focus is more difficult.

The general pattern of Behavioural Family Therapy is as follows:

1. Meeting with the family to discuss the benefits of the approach.
2. Agreeing with the family that they are willing to try the approach.
3. Assessment of individual family members.
4. Assessment of family communications and problem-solving.
5. Formulation by the family worker of family resources, problems and goals. This is done in collaboration with the family.
6. Meeting with a family to discuss/plan how to proceed, and establishment of family meetings without the family worker.
7. Sharing of information about the disorder and its impact.
8. Communication skills training.
    - Active listening
    - Expressing positive requests
    - Making positive requests
    - Expressing unpleasant feelings
9. Problem solving.
10. Booster sessions.
11. Disengagement from the family if appropriate.

It is important to remember these are general guidelines, and there are times when the sequence will be different because of the needs of the particular family. For example, the family may be in the middle of a crisis when the first contact with them is made, and the family worker may have to introduce Problem Solving before the different assessments can take place. Another situation is where the family members are already proficient in a particular skill eg making requests of each other. In this case, the family worker would not need to spend time on the ‘Making Positive Requests’ module.

The main points for the family worker to remember are that the approach is structures though not rigid in nature, is flexible, and most of all is responsive to the needs of the family and the individual family members.

Appendix B.2: Invitation Letter and Opt-in Form

Staffordshire & Keele Universities Doctorate in Clinical Psychology

DClinPsy

Faculty of Health Sciences, Staffordshire University,
Leek Road, Stoke-on-Trent ST4 2DF
E DClinPsy@staffs.ac.uk
T +44 (0)1782 - 294007
W http://www.staffs.ac.uk

Dear reader,

My name is Rachael Edge and I am a Trainee Clinical Psychologist. I am doing a research study into the experiences of families, or other groups of people, when one person experiences a first episode of psychosis and the family or group has Behavioural Family Therapy (BFT) following this.

I have asked your clinician to help me find people who might be willing to participate in this research, and this is why they have given you this letter. There is no obligation for you to participate and if you chose not to, the support you receive from the Early Intervention Service will not change in any way. If you think you might be interested then please read on.

What is the research about?

The aim of my research is to explore how those who have taken part in BFT have developed a shared understanding of what has happened, and how this might have helped them.

What will happen?

If you take part, you and those who attended BFT with you, will be interviewed by me, altogether. It will be a one-off interview, somewhere convenient for you, lasting for approximately an hour. I will ask you all about your shared experience of one of you experiencing psychosis and all of you attending BFT. In the interview, questions will be asked to the whole family (or whoever did BFT with you), and it will be up to you as a group to answer how you want to. This means that sometimes you might all say something, and other times some people in the group may not say anything. Both of these are OK.

I will record the interview on an audio recorder, then after the interview I will take this away and write out everything that was said in the interview, word for word. I will then read through this, looking for the shared understandings you have as a group about your experiences. I will compare what I find to findings from other families' interviews, looking for any similarities or differences.

Is it confidential?

All efforts will be made to keep you participation confidential - it is up to you if you tell anyone you are taking part. When your audio recorded interview is written down, your name will be changed. In the research report, quotations of things you have said may be used, but your name will be changed there too.

What are the risks or benefits to me?

You might find it difficult to talk about your experiences, or to hear others talking about theirs. You can stop the interview and withdraw from the study if you are finding this difficult, but if you think this will be too hard for you, you may not want to take part at all. This is OK.

You will not feel any specific benefits for taking part in this research, however the findings may help with the development of services and support for families and groups in the future.

What now?

If you do not want to take part in this research, that is OK. Please tell your clinician.

If you think you might be interested in taking part, and would like to know more about the research, please complete the opt-in slip at the bottom of this letter. Even if some of those who completed BFT with you definitely don't want to take part, we can still do the interview if at least two of you are present.

Give the opt-in slip to your clinician, who will then give you a 'participant information sheet', which contains more detailed information about the research and which should answer any questions you may have. Your clinician can go through this information sheet with you if you want this. The opt in slip will be given to me, and I will contact you on the number you have provided, to answer any questions, and to arrange an interview date if you would like to take part. If you would rather nominate one member of your family for me to contact, you can do this on the opt-in slip, but if you think later that you would like to speak with me separately, this can still be arranged. Remember you can change your mind at any time, and completing the opt-in slip does not make you obliged to take part.

Thank you for taking the time to read this letter.

Yours Faithfully,

Rachael Edge
Trainee Clinical Psychologist
Staffordshire and Keele Universities.

Opt-in slip

I would like to know more about this research study, and would like the researcher to contact me.

Name _____ Contact Number _____

I would like to nominate a member of my family / other person who completed BFT with me, for the researcher to contact on my behalf. *(Please circle):* **YES** **NO**

If yes, please put their name here: _____

If nominating someone else to be contacted, this person must have completed the BFT with you and must also be interes in the research. They must also complete an opt-in slip, with a contact number provided.
Tick here if you have been nominated as the contact for your family/group ☐

To be completed by your clinician

Date slip collected _____ Clinician name _____

Appendix B.3: Participant Information Sheet

PARTICIPATION INFORMATION SHEET

Title of Project: Family Narratives of First Episode Psychosis and Behavioural Family Therapy

Name of Researcher: Rachael Edge

INTRODUCTION

We would like to invite you to take part in our research study. You have been given this information sheet because you have chosen to 'opt in' to find out more about this study. Before you decide whether to take part we would like you to understand why the study is being done and what it would involve for you. Please read through this information sheet to find out this information. We'd suggest this should take about 15 minutes. Talk to others about the study if you wish. The information sheet is broken down into two parts:

Part 1 tells you the purpose of this study and what will happen to you if you take part.

Part 2 gives you more detailed information about the conduct of the study.

You will be contacted by the researcher on the number you have given on the 'opt in' slip, who can answer any questions you have about the study, and arrange an interview date with you if you wish to take part. If you have nominated a family member for the researcher to contact, please pass on questions you have on to them. You can still speak to the researcher even if you have nominated a family member as your main contact. Details of how to contact the researcher are contained in this information sheet.

You can keep this information sheet. There is space at the end of this sheet for you to note down any questions or concerns you would like to discuss with the researcher.

PART 1

Here we will tell you the purpose of this study and what will happen to you if you take part.

WHAT IS THE PURPOSE OF THE STUDY?

• This research study aims to find out more about the journey made by families, when one family member experiences a first episode of psychosis and the family has Behavioural Family Therapy (BFT) following this.
• The research will look at families' understanding of what has happened, after they have had BFT. This understanding will be explored through the 'narratives' created by families; the stories they share and tell about their experience.
• By 'family', we mean anyone who has taken part in BFT, even if this includes friends, carers, or people who live together but are not family. Whenever we use the word 'family' here, this will include any group of people who have completed BFT together.

WHY HAVE I BEEN INVITED?

• You, and some of your family members, or other people who are close to you, have decided to have Behavioural Family Therapy. This means that if you choose to, you can take part in this study.
• We are asking between 5 and 8 families to take part in this study.

DO I HAVE TO TAKE PART?

• It is up to you to decide to join the study. This information sheet describes the study. If you and your family members agree to take part, the researcher will arrange an interview date.
• You are free to withdraw from the study, without giving a reason, at any time, until the study has been published.
• If your family members wish to take part in the study, but you don't, they can participate without you.
• Not taking part or withdrawing from the study will not affect the standard of care or any treatment you receive.

WHAT WILL HAPPEN TO ME IF I TAKE PART?

• If you agree to take part, you will take part in an interview, along with some or all of your family who attended Behavioural Family Therapy with you.

The Interview...

• will last approximately one hour, but may go up to one and a half hours.
• will take place at a location familiar to you, such as your local Early Intervention service, or with your permission, at home.
• will be audio recorded on a digital audio recorder.

• The researcher will ask questions about everyone's shared experience of one of you experiencing psychosis, and also about everyone's shared experience of taking part in Behavioural Family Therapy.
• Details of what will happen to the audio recordings are included in Part 2.

WHAT WILL I HAVE TO DO?

• The researcher will arrange an interview date and time which is suitable for you all.
• You will either be asked to attend a setting familiar to you, such as your Early Intervention service, or to allow the researcher to visit you at home, to take part in the interview.
• Before the interview you will be asked to complete a consent form. This is to say that you have understood what you have read in this information sheet and that you agree to take part in the study. If you are under 16, a parent or carer will also sign your consent form.
• Before the interview you will be asked for some basic information, including your role in the family (e.g. mother, father, sibling, friend), your gender, ethnicity and whether you have any disabilities. You will also be asked whether you are the main service user who experienced psychosis, and approximately when you completed Behavioural Family Therapy.
• The researcher will then ask you all some questions altogether in an informal interview, where everyone can contribute to answering.
• The interview will be audio recorded.
• Once enough families have taken part in the study, the researcher will not interview any more. You and your family will be given time to decide whether you wish to take part, but if in the mean time all of the interviews have been completed, your clinician or the researcher will inform you of this.

WHAT ARE THE POSSIBLE DISADVANTAGES AND RISKS OF TAKING PART?

• By taking part in the interview, you will be asked to talk about your shared experience of one of you experiencing psychosis and you all attending Behavioural Family Therapy after this. You will also be asked about what you think the future may be like for you as a family.
• Talking about your experiences, or hearing others talk about theirs, may be difficult and there is a risk that this might affect the way you feel. If you feel that this will be too difficult for you, you may not want to take part in this study. If you begin to take part but find that it is too difficult for you, the interview can be stopped at any time and you can either take a break from the interview or withdraw from the study altogether.
• If you are under 16, or if you are a parent or carer of someone under 16 who might like to take part, you should consider whether participation may be too difficult for the person under 16, based on the risks explained above.
• There are no other known risks of participating in this study.
•We will make sure that your participation in the study is confidential and anonymous. You can find out more about this in Part 2 of this information sheet.

WHAT IF THERE IS A PROBLEM?

Any complaint you have about the study, during or after your participation, will be addressed. Detailed information on this is given in Part 2 of this information sheet.

WILL MY TAKING PART IN THE STUDY BE KEPT CONFIDENTIAL?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. You can find out more about this in Part 2 of this information sheet.

This is the end of Part 1
If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

PART 2

Here we will give you more detailed information about the conduct of the research.

WHAT WILL HAPPEN WITH THE AUDIO RECORDINGS?

• The audio recordings of your interview will be written down word for word by the researcher.
• The audio recordings and written versions of these will then be used by the researcher to identify and describe your family's journey, as described by you all in the interview.
• The audio recordings and written versions will be stored securely, and names will be changed in the written versions, to maintain anonymity.
• The audio recordings will be destroyed once the study has finished, which we anticipate will be September 2015.

WHAT WILL HAPPEN IF I DON'T WANT TO CARRY ON WITH THE STUDY?

• Even if you agree to take part in this study, you can change your mind at any time before the interview takes place, during the interview, or up until the research is published. This is called your right to withdraw.
• If all parents or carers of someone under 16 decide to withdraw themselves from the interview, the person under 16 will also be automatically withdrawn from the interview. This is because it is important for a parent/carer to be present to ensure that the young person does not become distressed during the interview, and if they have concerns about this, to suggest their withdrawal.
• If you decide that you do not want to take part in the study, the support and treatment you and your family receive from the Early Intervention service will not change.
• Even if you arrange an interview with the researcher, it is OK to change your mind.
• If you decide that you no longer want to take part in the study after the interview, your contribution to the interview will be excluded during analysis of the interview, and you will not be included in the research report.

WHAT IF THERE IS A PROBLEM?

If you have a concern about any aspect of this research, you can:

• talk to the researcher, if you have a concern during the interview.
• talk to your clinician, who may be able to take action to address this.
• ask to speak to the researcher who will do their best to answer your questions. Your clinician can arrange for the researcher to contact you.

• If you remain unhappy and wish to complain formally, you can do this by contacting the Patient Relations Team, on 01*** ******, or ***@****.nhs.uk.

While you take part in this study, you will remain in the care of the Early Intervention Team. Please continue to access this service for support as and when you need to, including if you feel you need some support following the interview.

Other organisations which provide support to people who have experienced psychosis, and their family and friends, include:

• MIND: 0300 123 3393; www.mind.org.uk
• Rethink: 0300 5000 927; www.rethink.org

WILL MY TAKING PART IN THE STUDY BE KEPT CONFIDENTIAL?

Every effort will be made to make sure that your participation in this study is confidential and anonymous.

• All data collected will be stored securely and anonymity will be maintained.
• Quotations of things you or others have said during the interview may be included in the research report, but names will be changed.
• No-one else will be told about your participation in this study.
• It is up to you and your family if you decide to tell anyone else that you and your family are participating in this study.

If, during the interview, you or another person who is taking part, disclose information which indicates that a young or vulnerable person is at risk, or that a crime will be committed, the researcher will need to pass this information on by law. They would need to pass this information on to your clinician, or to ****** Safeguarding Board or the police.

WHAT WILL HAPPEN TO THE RESULTS OF THE RESEARCH STUDY?

• The researcher will write a research report, which may include a quotation of something you have said. If this happens, your name will be changed in the report. The quotation might be linked to your gender, ethnicity, role in the family, any disabilities, how long ago you completed Behavioural Therapy, and whether you were the person who experienced problems leading to your involvement with Early Intervention services.
• If you would like to see a summary of the report once it has been completed, you can contact the researcher via the Clinical Psychology Programme. Contact details are at the end of this form. It is hoped that the report will be complete by September 2015.

• The research report will be publicly available, however, your anonymity will be maintained.

WHO IS ORGANISING THE RESEARCH?

This research is organised as part of the Doctorate in Clinical Psychology training, which is sponsored by Keele University. If you would like to know more about this, you can ask the researcher. Contact details for Keele University are included at the end of this information sheet.

WHO HAS REVIEWED THE STUDY?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This research has been reviewed and given favourable opinion by an NHS Research Ethics Committee. This research has also been reviewed and approved by Keele University, and by the Research and Development Team for ********** NHS Trust.

GENERAL INFORMATION ABOUT RESEARCH

Research is an important part of the work done in the NHS. The aim of research is to find better ways of looking after patients and keeping people healthy. NHS patients benefit from past research and research which is currently being carried out. A lot is known about the problems that bring people to the NHS, but there is still more to learn. Research can help with this learning, filling gaps in knowledge and changing the way that healthcare professionals work, in order to improve treatment, care, and quality of life.

For more information visit: http://www.nhs.uk/conditions/clinical-trials/pages/introduction.aspx

If you would like independent advice about participating in this study, you can contact the Patient Relations Team on 01*** ******, or p***@****.nhs.uk.

WHAT ARE THE BENEFITS OF DOING THIS RESEARCH?

• If you choose to take part in this study, you will not feel any benefits of the research yourself.

• However, better knowledge of families' experiences might help clinicians and services in their delivery of support and services in the future.

WHAT DO I GET FOR DOING THIS RESEARCH?

• Your participation in this study is voluntary. This means that you will not be paid or given any other reward for taking part.

• It is important that if you decide to take part, you do this just because you want to, and not because of any other incentive, like being paid.

ORGANISATIONS INVOLVED IN THIS RESEARCH

This research is taking part within ******* NHS Trust.

• If you have questions about this organisation, or would like advice, you can contact the Patient Relations Team, on 01*** ******, or p***@****.nhs.uk.

• Dr **** *****, Clinical Psychologist, is facilitating this research within the ******* Early Intervention in Psychosis Team. If you have any questions about the research, you can contact her on 01*** ******

Keele University is the sponsor of this research, through the Doctorate in Clinical Psychology Programme.

• Dr Helena Priest, Chartered Psychologist and Senior Lecturer in Clinical Psychology, is supervising this research project. If you have questions about the research, you can contact her on 01*** ******

• Rachael Edge is the researcher for this project. If you would like to speak to her, please tell your clinician, or contact the Clinical Psychology programme on 01*** ******

This is the end of the participant information sheet. You, or your nominated family member will be contacted shortly by the researcher to discuss any questions, and to arrange an interview date if you would like to take part.

YOUR NOTES

Use the space below to note down any questions or concerns you would like to discuss with the researcher.

Appendix B.4: Consent Form

PARTICIPANT CONSENT FORM

Title of Project: Family Narratives of First Episode Psychosis and Behavioural Family Therapy

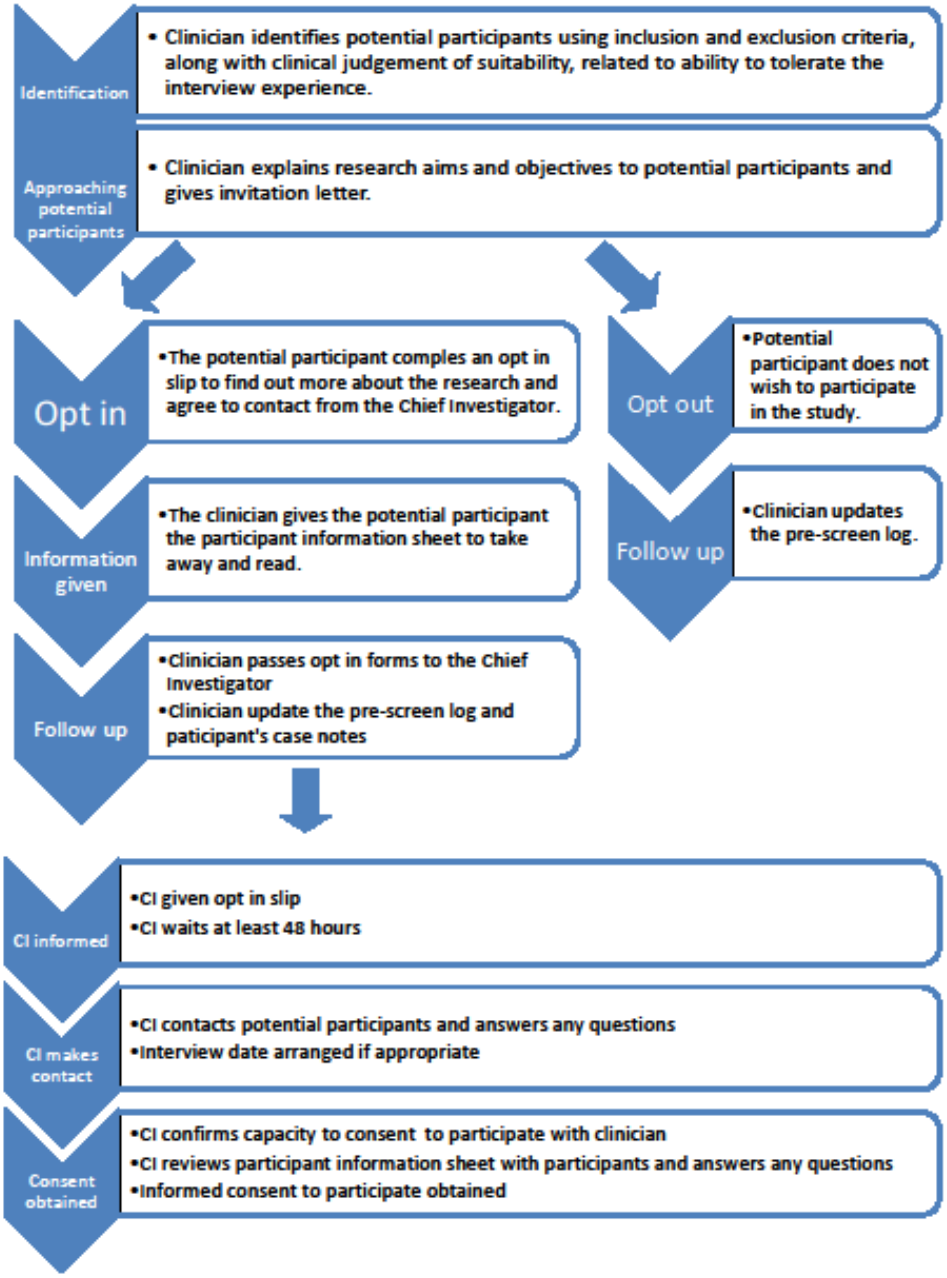
Name of Researcher: Rachael Edge

		Tick	Initials
1.	I confirm that I have read and understand the information sheet dated ***14th April 2014 (version 3***) 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 before, during or after my interview, up until the research is published, without giving any reason, and without my medical care or legal rights being affected.	☐	_____
3.	I agree to being audio recorded during the interview, and for this audio recording to be used for the research described in the information sheet.	☐	_____
4.	I understand that the following information will be included in the research report: my gender, ethnicity, role within the family (eg, mother), any disabilities I might have, whether I am the person who experienced psychosis, and approximately how long ago I completed Behavioural Family Therapy. I understand that my name and other identifiable information will be changed in the report.	☐	_____
5.	I understand that quotations of things that I have said while being audio recorded might be used in the research report. I understand that my name will be changed in the research report but that quotations might be linked to my gender, ethnicity, any disabilities, family role, whether I am the person who experienced psychosis, and how long ago I completed BFT.	☐	_____
6.	I agree to take part in the above study.	☐	_____

_____ _____ _____

Name of Participant Date Signature

Appendix B.5: Overview of Recruitment Process



Appendix B.6: Interview guide

INTERVIEW GUIDE

During the interview, encourage the participants to share the following:

• How things were for the family before the psychosis began, and before their engagement with services.

• What it was like for the family when the difficulties began.

• How things were for the family when they began engaging in services

• What stands out for the family during the time they engaged in BFT, considering any struggles, highlights, and turning points.

• What things are like for the family at present

• How the family sees the future being for themselves.

Appendix B.7: Emden's (1998) Method of Creating a Core Story

1. Reading the full interview text within an extended timeframe to grasp its content.
2. Deleting all interviewer questions and comments from the full interview text.
3. Deleting all words that detract from the key idea of each sentence or group of sentences uttered by the respondent.
4. Reading the remaining text for sense.
5. Repeating steps three and four several times, until satisfied that all key ideas are retained and extraneous content eliminated, returning to the full text as often as necessary for rechecking.
6. Identifying fragments of constituent themes (subplots) from the ideas within the text.
7. Moving fragments of themes together to create one coherent core story.
8. Returning the core story to the respondent and asking 'Does it ring true?'

Appendix B.8: Stage by Stage Example of the Analysis Process

Stage 1: Raw Interview Transcript

C: Well I think that we used to attack [S: yea], and now we don't.

S: All of us, we would say something, Gayle would bite back, and you know, we didn't actually get anywhere with it. We were both, all like, it sounds like we were fighting all the time which is not true [I: No], but we didn't actually resolve things did we? Whereas now we'll, I, say it was me and Gayle I would think generally more carefully about how I phrase something or how I expressed it so that she really understood what it was that I was asking, erm, and you would take more time to think about it and answer what you felt really [G: yea], erm and she understood through all of this that it's OK that we don't agree, you know, and it's alright to say "well OK, but that's not what I feel" [I: yea], erm and like get a discussion rather than not agree with it but be saying "OK", and then be cross [G: yea] [I: yea], you know. There were lots of issues like that. We probably didn't even realise we were doing it, did we? [G: no] [C: no] But it made us...

C: But you don't answer now "I don't know". Whenever that happened, before the family meetings, and I suppose before you were ill, erm, if you said to Gayle "why have you done that, what's this?", "I don't know, I don't know", and when you're 20, that's quite frustrating when that's the only answer you get, and you don't say that at all now do you? [S: You never say it] You never say it, you say...

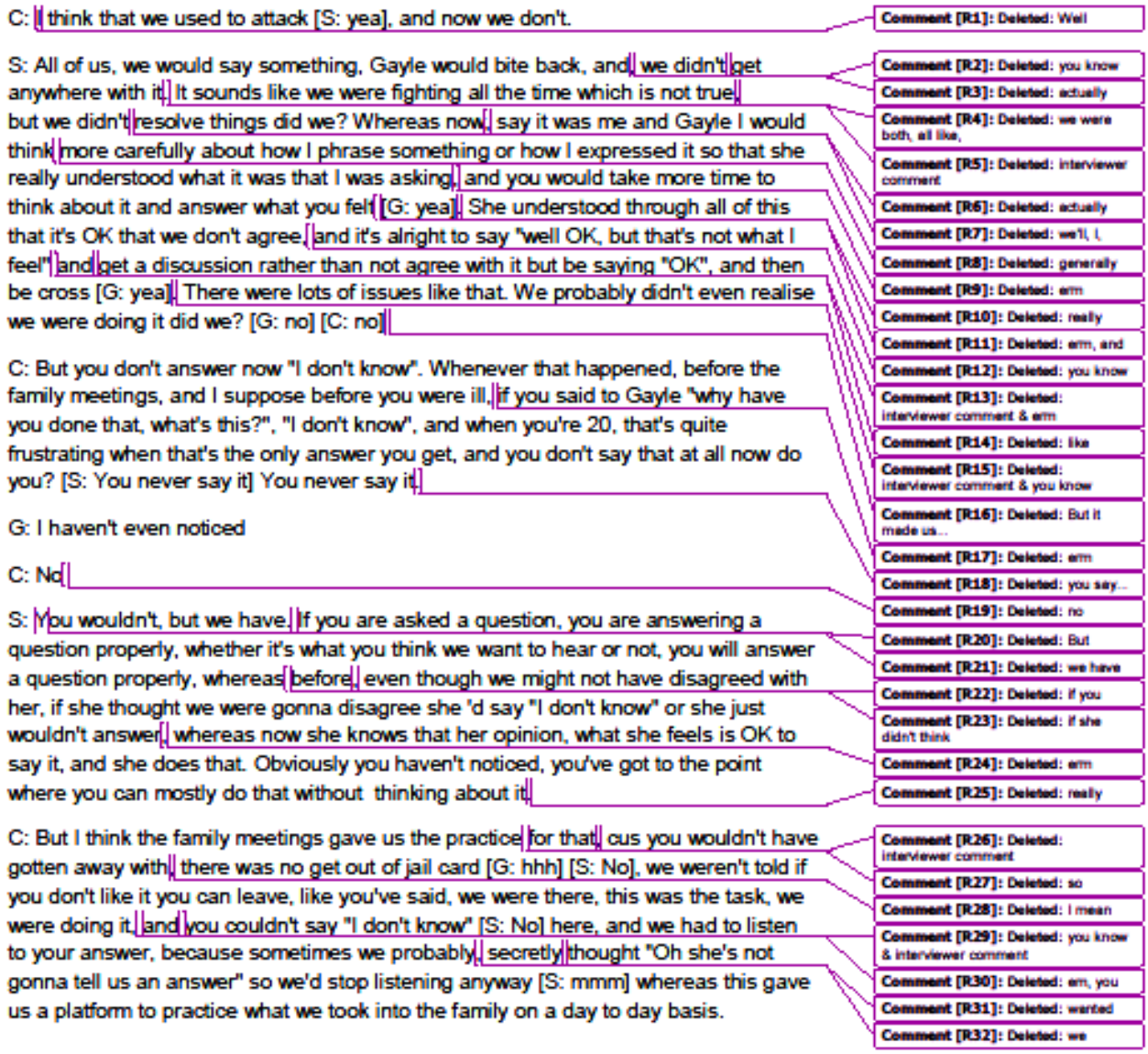
G: I haven't even noticed

C: No, no

S: But you wouldn't, but we have, we have, if you are asked a question, you are answering a question properly, whether it's what you think we want to hear or not, you will answer a question properly, whereas if you, before if she didn't think, even though we might not have disagreed with her, if she thought we were gonna disagree she 'd say "I don't know" or she just wouldn't answer, erm, whereas now she knows that her opinion, what she feels is OK to say it, and she does that. Obviously you haven't noticed, you've got to the point where you can mostly do that without thinking about it really.

C: But I think the family meetings gave us the practice [I:yea] for that so, cus you wouldn't have gotten away with, I mean there was no get out of jail card [G: hhh] [S: No], we weren't told if you don't like it you can leave, like you've said, we were there, this was the task, we were doing it, you know [I: yea] and em, you, you couldn't say "I don't know" [S: No] here, and we had to listen to your answer, because sometimes we probably wanted, secretly we thought "Oh she's not gonna tell us an answer" so we'd stop listening anyway [S: mmm] whereas this gave us a platform to practice what we took into the family on a day to day basis.

Stage 2: Deleting interviewer questions and comments, and words superfluous to the meaning of each sentence.



Stage 3: 'Restorying' - phases of the journey identified

Past Phase: Before Help Obtained

C: I think that we used to attack [S: yea], and now we don't.

S: All of us, we would say something, Gayle would bite back, and, we didn't get anywhere with it. It sounds like we were fighting all the time which is not true, but we didn't resolve things did we? Whereas now... There were lots of issues like that. We probably didn't even realise we were doing it did we? [G: no] [C: no]

C: Before the family meetings, and I suppose before you were ill, if you said to Gayle "why have you done that, what's this?", "I don't know", and when you're 20, that's quite frustrating when that's the only answer you get.

Past Phase: Having BFT

C: You wouldn't have gotten away with, there was no get out of jail card [G: hhh] [S: No], we weren't told if you don't like it you can leave, like you've said, we were there, this was the task, we were doing it, and you couldn't say "I don't know" [S: No] here, and we had to listen to your answer, because sometimes we probably, secretly thought "Oh she's not gonna tell us an answer" so we'd stop listening anyway [S: mmm] whereas this gave us a platform to practice what we took into the family on a day to day basis.

Present Phase: How things are now

S: Say it was me and Gayle I would think more carefully about how I phrase something or how I expressed it so that she really understood what it was that I was asking, and you would take more time to think about it and answer what you felt [G: yea]. She understood through all of this that it's OK that we don't agree, and it's alright to say "well OK, but that's not what I feel" and get a discussion rather than not agree with it but be saying "OK", and then be cross [G: yea].

C: You don't answer now "I don't know". You don't say that at all now do you? [S: You never say it] You never say it.

G: I haven't even noticed

C: No

S: You wouldn't, but we have. If you are asked a question, you are answering a question properly, whether it's what you think we want to hear or not, you will answer a question properly, whereas before, even though we might not have disagreed with her, if she thought we were gonna disagree she 'd say "I don't know" or she just wouldn't answer, whereas now she knows that her opinion, what she feels is OK to say it, and she does that. Obviously you haven't noticed, you've got to the point where you can mostly do that without thinking about it.

C: But I think the family meetings gave us the practice for that

Stage 4: Fragments of themes identified and grouped together to produce subplots.

Past Phase: Before Help Obtained

Subplot: Everyone attacking

C: I think that we used to attack [S: yea], and now we don't.

S: All of us, we would say something, Gayle would bite back, and, we didn't get anywhere with it. It sounds like we were fighting all the time which is not true, but we didn't resolve things did we? Whereas now...There were lots of issues like that. We probably didn't even realise we were doing it did we? [G: no] [C: no]

Subplot: Communication bad

C: Before the family meetings, and I suppose before you were ill, if you said to Gayle "why have you done that, what's this?", "I don't know", and when you're 20, that's quite frustrating when that's the only answer you get.

Past Phase: Having BFT

Subplot: Process of BFT

C: There was no get out of jail card [G: hhh] [S: No], we weren't told if you don't like it you can leave, like you've said, we were there, this was the task, we were doing it, and you couldn't say "I don't know" [S: No] here, and we had to listen to your answer, because sometimes we probably, secretly thought "Oh she's not gonna tell us an answer" so we'd stop listening anyway [S: mmm] whereas this gave us a platform to practice what we took into the family on a day to day basis.

Present Phase: How things are now

Subplot: Changes noticed

S: We still carry on with that [G: yea] in the way we attack things that were difficult before, the way we speak to each other are different than they were before. Say it was me and Gayle I would think more carefully about how I phrase something or how I expressed it so that she really understood what it was that I was asking, and you would take more time to think about it and answer what you felt [G: yea]. She understood through all of this that it's OK that we don't agree, and it's alright to say "well OK, but that's not what I feel" and get a discussion rather than not agree with it but be saying "OK", and then be cross [G: yea].

C: You don't answer now "I don't know". You don't say that at all now do you? [S: You never say it] You never say it.

G: I haven't even noticed

C: No

S: You wouldn't, but we have. If you are asked a question, you are answering a question properly, whether it's what you think we want to hear or not, you will answer a question properly, whereas before, even though we might not have disagreed with her, if she thought we were gonna disagree she 'd say "I don't know" or she just wouldn't answer, whereas now she knows that her opinion, what she feels is OK to say it, and she does that. Obviously you haven't noticed, you've got to the point where you can mostly do that without thinking about it.

C: But I think the family meetings gave us the practice for that.

Stage 5: Identification of family narratives

Past Phase: Before Help Obtained

Subplot: Everyone attacking

C: I think that we used to attack [S: yea], and now we don't.

S: All of us, we would say something, Gayle would bite back, and, we didn't get anywhere with it. It sounds like we were fighting all the time which is not true, but we didn't resolve things did we? Whereas now...There were lots of issues like that. We probably didn't even realise we were doing it did we? [G: no] [C: no]

Comment [R1]: Narrating about all the family's behaviour, identifying unhelpful patterns, agreement from other family members.

Subplot: Communication bad

C: Before the family meetings, and I suppose before you were ill, if you said to Gayle "why have you done that, what's this?", "I don't know", and when you're 20, that's quite frustrating when that's the only answer you get.

Comment [R2]: An individual narrative from mom.

Past Phase: Having BFT

Subplot: Process of BFT

C: There was no get out of jail card [G: hhh] [S: No], we weren't told if you don't like it you can leave, like you've said, we were there, this was the task, we were doing it, and you couldn't say "I don't know" [S: No] here, and we had to listen to your answer, because sometimes we probably, secretly thought "Oh she's not gonna tell us an answer" so we'd stop listening anyway [S: mmm] whereas this gave us a platform to practice what we took into the family on a day to day basis.

Comment [R3]: Narrating how all the family had to do the task, how Gayle couldn't say "I don't know", and her parents couldn't stop listening. Considering what they took into the family as a whole. Agreement from other family members.

Present Phase: How things are now

Subplot: Changes noticed

S: We still carry on with that [G: yea] in the way we attack things that were difficult before, the way we speak to each other are different than they were before. Say it was me and Gayle I would think more carefully about how I phrase something or how I expressed it so that she really understood what it was that I was asking, and you would take more time to think about it and answer what you felt [G: yea]. She understood through all of this that it's OK that we don't agree, and it's alright to say "well OK, but that's not what I feel" and get a discussion rather than not agree with it but be saying "OK", and then be cross [G: yea].

Comment [R4]: Narrating how they have changed how they communicate, and including Gayle's perspective, with agreement from Gayle.

C: You don't answer now "I don't know". You don't say that at all now do you? [S: You never say it] You never say it.

G: I haven't even noticed

C: No

S: You wouldn't, but we have. If you are asked a question, you are answering a question properly, whether it's what you think we want to hear or not, you will answer a question properly, whereas before, even though we might not have disagreed with her, if she thought we were gonna disagree she 'd say "I don't know" or she just wouldn't answer, whereas now she knows that her opinion, what she feels is OK to say it, and she does that. Obviously you haven't noticed, you've got to the point where you can mostly do that without thinking about it.

C: But I think the family meetings gave us the practice for that.

Comment [R5]: Individual contributions to create a shared understanding about a subject. Considering others' perspectives and sharing feedback.

Appendix B.9: Main Subplots and Themes

Phase / Broad Aspect	Past: Being Ill / Before Help Obtained	Past: Journey into Services	Broad Aspect: Diagnosis	Past: Doing BFT	Broad Aspect: Involvement with EI	Present: How Things are Now	Future
Subplots & Themes	**Not getting on** • Poor communication • Arguments **Illness as a shock** **Responses to symptoms / behaviour** • Masking / misattribution of symptoms • Not knowing what was wrong • Impact on work	**Seeking & not receiving help** • Intervention too late • What if? stories **Hospitalisation** • Traumatic • Worries about returning to hospital **First contact with EI team**	**Ideas of mental illness** • Seeking a diagnosis •Disagreement with diagnosis **Impact of diagnosis** • Benefits • Explaining everything	**What doing BFT was like** **Aspects of the BFT which were helpful/hard** • Specific exercises helpful • Hard aspects still helpful **Involving others / impact of BFT on others**	**Benefits** • Individual support • Help with work • Social activities • Familiarity & continuity	**Improvements noticed** **Improved communication** **New understandings** • Of the illness • Of each other **VS** **Not getting better**	**Legacy & role of EI team** **Role of milestones in recovery** • Work important

Appendix B.10: Subplots and Themes Found Within Each Families' Narrative

Family 1

Phase	Subplot	Theme	Examples
Past: Before Help Obtained	Communication bad	Everyone 'attacking'	*C: I think that we used to attack [S: yea], and now we don't.* *S: All of us - we would say something, Gayle would bite back, and, we didn't get anywhere with it. It sounds like we were fighting all the time which is not true, but we didn't resolve things, whereas now...There were lots of issues like that. We probably didn't even realise we were doing it [G: no] [C: no].*
	Response to symptoms	• Not knowing what was wrong • Gayle trying to deal with it alone	*S: We didn't even know that what was wrong with her, or if there was any issue of any kind, she was always trying to deal with it on her own, without telling anybody else what she was feeling. You were not well for quite a long time before, although none of us know what was the matter, she was plodding along.*
Past: Hospitalisation	Hospitalisation scary & horrendous	• Gayle can't remember being hospitalised • Really poorly	*S: We got to the hospital with the police escort hhh we caused lots of excitement hh [G: hhh] [C: Really scary]. And she was quite calm when we got to the hospital, and we went in to the triage nurse.* *G: I don't remember* *S: No, you wouldn't remember any of that Gayle because you were not with us really.*
	Coming out of hospital difficult - gradual process	Thinking she'd never leave hospital	*S: I don't think she thought she was ever gonna come out [G: yea].*

			G: And I came out! hh *C: "Really am I coming home?"* *S: Yea, she thought she'd never get out*
	Finding out about wider family mental illness during hospitalisation	Comparing experiences to other family members	S*: It was during that time that she was in hospital that we talked with the doctors, that there was mental history in her family, so she was still in hospital when she got an understanding that there was a family history. When we got to the hospital and we went in to the triage nurse, she asked then if there was any family history, and I said yes, there was, her mum had mental illness and you just looked at me like that.*
Past: Doing BFT	What doing BFT was like	• Privacy good • Hard but useful • Sharing the problem & responsibility	*C: It was quite nice to be shut away in this room, like we are now, and be able to say anything and it didn't go out of the room, and that we could be honest with each other.* *-----* *S: It wasn't just Gayle, that was the thing that was important, we all had to look at the things that we were saying, about Gayle...not only things are not right, but they're not right with any of us in a way.*
	What was helpful about the BFT	• A good platform to start from - psychoeducation • Making a positive request • Practising communication • Enabling understanding	*S: The first most important thing was describing what psychosis was, for all of us. None of us had got any idea what it was, or why it had happened, and for us to talk about that and hear about it as a family for me was really important, that was a good start [C: yea] for us to move on.* *G: It was really helpful for me cus I'd gone through it and didn't even know what it was, so I needed to hear it [S: Yea].*

	What wasn't so helpful during BFT	• Something we already did	*S: It was something that we felt was already covered, or maybe something that we already did anyway...The ones that stand out are the ones that we didn't do, it was very noticeable that we don't do it, those were the ones that were more important.*
	Involving other daughter	• Logistical difficulties • Helping wider understanding	*C: I think it just heightened her awareness [S: yea]* *S: And one meeting she couldn't come to that she wanted to, so we did it, and [C: yea that's right], she came the next day, and we had to go through it with her and she did end up getting upset then* *C: She cried then* *S: Cus she was saying "Oh I should have done this" and "I could have done that". But from a practical point of view, although that may be beneficial I can see that that's quite a difficult thing to put into place.*
Broad Aspect: Other Support from the EI Team	Importance of individual support for Gayle	• Social activities • Someone to talk to	*S: What's been nice as well, there's been times for Gayle to do things with Sophie, that have been for her, where she can talk about how she feels, what's happened.*
	Benefits of EI team involvement	• Over and above what expected • Help with talking to work • Familiarity	*S: But they were there even when Gayle went back to work... Because the team were there, it wasn't like we were just making a fuss, they were there, and Gayle's manager then was great, she did the phased return.*

Past: Towards Recovery	Building independence	• Meals and holidays	*S: Initially we couldn't even go out for a meal or anything, couldn't leave Gayle, she couldn't stay on her own [G: no].... recently went away, we'd got a cruise planned. We'd planned it so that we'd do a cruise for two weeks and Gayle has been on her own for two weeks, so, she was fine .*
	Progressing with job		*S: When you said that you'd seen that job advertised in {restaurant} and you thought you might like to do that, that was a little thing that was a big thing for me. She's recently just asked at {restaurant} to switch a job slightly, but you were able to voice and say I'm not ready to move on from {restaurant} yet, but I want to change what I'm doing, so she's going to be working, what they call, the lobby.* *G: Well, cus I'd done it, been trained to do it before, I just thought, when I was eventually ready to move on, it would be a better experience, just to get back into it. Cus I'll still be earning money, it's just I'll be re-training myself, ready for it.* *S: The fact that you'd thought about that yourself, and made the move yourself, was a big deal [C: and told us].*
Present: How Things are Now	Changes noticed	• All noticing • Celebrating progress	*G: It helped a lot because I've noticed you don't nag anymore [S: No] But I, also don't bite back anymore either.* *S: No, and it makes such a difference, I can ask something and she'll answer properly, and it's done - that would have been a nagging session before.*
	Better communication	• BFT becoming a way of life	*C: I think a lot of the behavioural therapy has now become a way of life [G: yea] [S: mm]. I'm not noticing it the same. Because you're right, but until you just said that now I hadn't thought about that, it was nice for her to tell us.*

Future	Optimism		*G: The only way is up [C: mm hmm] from here.*
	Legacy & role of EI team	• Toolkit • Continued activities	*C: They've probably given us a toolkit of things that we can use, and ways of recognising if things are perhaps going a little bit wrong. We won't be left to drift at the end of two years, we'll be fully equipped to hopefully prevent something else from happening.*
	Progressing in job		*S: In terms of jobs, when you think you're fed up of it, being able to think, "OK, I've had enough now, what do I want next?"*

Family 2

Phase	Subplot	Theme	Examples
Past: Before Help Obtained	Not getting on	Blame	*A: There was a time where none of us got on with each other, it was really tense. It isn't like that anymore is it? [M: No]. As a family when you're all living under one roof together, you've all got to get on. Before we didn't and it was a horrible atmosphere all the time weren't it? I think Mark used to think that we were always on his back. Cus before I'd be the prime person for shouting and bawling at the top of the stairs and not getting the response I wanted, and then shouting and bawling even more, which would make you angry wouldn't it? And then Mark'd get all frustrated and we wouldn't get anywhere. Whereas now it's very different.*
Past: Journey into Services	Seeking help and not getting it	• Intervention too late	*A: I know Mike, Mark's dad had tried to access help before, I think by the time, the early intervention team did get involved, it was at the point of crisis and it was almost, too late for Mark to be treated. If the GP had've responded differently, maybe it wouldn't have come to the situation it did.*
	Traumatic sectioning	• Mark willing for help initially, then frustrated and unwilling • Traumatic sectioning experience • Took a while to accept he was poorly	*A: I think originally, Mark was quite, keen to have, outside help... and then when they went out to see him, later on, it was quite late in the evening Mark had, understandably, got himself into a bit of a state, and was quite upset, and one thing led to another and the police ended up being called and they were quite, aggressive with you and it got to the point where I think*

		• Mark struggles to talk about	*Mark was really upset, quite frightened, and then wouldn't agree that he needed help, so that, decision got taken out of his hands and, he ended up, then getting sectioned, and taken to hospital... For quite a while after you went into hospital, you-he, Mark still struggles to talk about the whole process, but after a while you did come to accept that you did need some help, and the medication and everything that's happened since, has helped and Mark is in a better place. I think it's taken Mark, a long time to, get over that, to accept that, although it wasn't handled in the right way what happened then and what's happened since has been obviously beneficial really.*
	Leaving hospital for home	• Home visits beneficial • Worries about returning to hospital	*A: Quite early on, he was allowed to come home and I know you got to the stage where, first of all it was only for like half an hour initially, and it wasn't long enough, and the more it was extended, they saw that the more beneficial it was for Mark so they did quite quickly extend your periods at home [M: yea]...that was quite scary for you [M: yea] thinking that if he said anything to anybody that he was gonna end up back in hospital again.*
	Contact with EI	• Good relationship with clinician helped acceptance of support	*A: When, Dave came on board, cus you do get on, really well with Dave, he's got quite a nice, trusting relationship with Dave...so I think when they were allocated, and they were coming, to visit Mark, having that, I suppose positive relationship helped him to, open up and to be more honest, and accepting of the support.*
Past: Doing BFT	Deciding together to	• Motivation to do it	*A: We talked about it and, we asked Mark and once*

	have BFT	• Agreeing they'd all benefit	*Mark agreed he was up for it, we thought it was something we'd all benefit from...I think it was because we were all quite motivated to do it, if any one of us was 50/50 about it, it wouldn't have worked.*
	What it was like	• Initially nerve-wracking, then easy • Having a mediator enabling honesty and perspective	*A: Although we discussed it first, we agreed, I think it was quite nerve wracking at first [M: yea]. The first couple of sessions we were* *M: A bit nervous* *A: Yea, and we were still a bit, reserved, but once we got into the swing of things, and went towards the middle of the sessions, and by the time we went on holiday, it all started to become quite, it was quite easy then to see the benefits.* *-----* *M: Having somebody else there that wasn't a member of the family helped.* *A: Dave or Mark always knew that if he found it difficult you could ask to stop, not that Mark ever needed to but I do agree with Mark, it's very different there, having somebody there to mediate.*
	Mark's motivation to work		*A: And Mark's always been up and ready, ready to go for it each session, which has been really good!*
	Involving sister	• Logistical difficulties	*A: Because of the sessions and the fact that the three*

		• Sharing work done	*of us have been able to talk more openly, Lisa has been there, like at teatime, when we've been talking more openly, so it's benefited Lisa, because she's now got a much better understanding of what Mark went through and what he experienced, and what let up to him being so poorly, and I think that's been really good for Lisa to see.*
	Helpful aspects of the BFT	• Timeline facilitating understanding • Triggers work helping with coping strategies • Both having copies of plans etc	*A: Mark was very open about when the symptoms started and how he was feeling at the time and what he was experiencing, cus up until then, I hadn't got any idea that it had happened that much further back, cus it went on for a long time before we even noticed, so that was a really big turning point and for me, it was when I started, not accepting, but having an understanding of why Mark was behaving the way he was and why he did some of the things he did.* *M: The timeline helped me understand how poorly I actually was before I got put into hospital.*
Present: How Things are Now	Improved communication	Being able to talk about taboo subjects	*A: If Mark does something that I don't particularly like and vice versa, we can now tell each other without flying off the handle, whereas there was a lot of that before. That's come from the family therapy, and being respectful of how you approach things, and when to approach things. I know how important it is for Mark that we have eye contact, and we're respectful, and now Mark's very much like that as well. He's not disrespectful anymore if you want something. So that's been a real change as well.*
	Honesty & confidence	• No longer smoking	*A: Me and his dad have got confidence in him, that if he*

		cannabis • Confidence in seeking help sooner if needed	*was feeling poorly again, we've now got the confidence that he would be able to say "look, mom I'm having a bit of a bad day", or, "I think I need to get in touch with Dave".*
	New understandings	• About symptoms • Of each other	*A: I think through doing the timeline and looking at different symptoms and how they affect you and just because he's feeling anxious, that's not necessarily a symptom of psychosis, there's different triggers and Mark now knows that or accepts that just because he was having a bad day or he felt low one day, it doesn't mean that he's gonna have a full blown psychotic episode and need hospitalisation again.* *M: Just going through the family work and the triggers and that explained, that if I'm feeling anxious, it's not, necessarily me, having a psychotic episode, it's just because I'm feeling a bit anxious, which is, mainly what I get now.*
	Changed relationships	• Part of the family	*A: We now get the sense that Mark wants to be part of the family again.* *M: I'm not so much on the outside anymore, I'm more on the inner circle again, instead of sitting on the sidelines watching. Getting involved in conversations, and making jokes, and asking for things properly and, not losing my temper so much.* *A: It's Mark wanting to be part of the family again, and us wanting him to be part of the family. 18 months ago, it was easier when he wasn't here, whereas now, it's unusual or it's not the same if he isn't here.*
	Recovery activities	Going for a walk	*A: He'll just put his headphones on and, he'll say I'm*

			going out for a walk, and you do quite often go for a walk and you get quite a lot out of it [M: yea} he's got the same route that he walks and you do it at least a couple of times a week *M: Yea* *A: And obviously it helps if you stay fit as well* *M: Yea*
Future	Continued involvement with EI	• To help independence	*A: I think you're gonna do some more one to one sessions with Dave aren't you, about supporting him, so meeting him in places, and Mark has to get there.*
	Big steps ahead (milestones), but no pressure	• Mentioned by parents, but recognising it's at his pace	*A: I suppose as Mark gets even better and gets more independent and wants to be going out more, and eventually going back to work or whatever he decides he wants to do, that'll be another big step for us all, cus he's certainly not ready for that at the moment so that'll be another big step. But I think we'll see that as a positive, cus it'll be another rung up the ladder in Mark's recovery. And obviously that's what we want for Mark, an end goal and having employment, and meeting somebody and whatever else, but I think me and his dad are quite respectful, and understand that that needs to happen at Mark's pace. Mark will do things when Mark's ready, and we know that if he says he doesn't want to do something, then it's genuinely because he doesn't feel that he can rather than he's just, I don't wanna do it.*
Broad Aspect:		• Initially distanced	*A: She really distanced herself, she didn't know what to*

Relationship with Sister		• Wider impact of BFT helped • Rebuilt relationship	*do and she hadn't got much time for him I suppose... That's impacted on Lisa as well which I think has really helped her rebuild her relationship with Mark.*

Family 3

Phase	Subplot	Theme	Examples
Past: Before Help Obtained / Being Ill	Not well understood - a shock		*T: And that was a shock, that didn't make any sense to him, whether it was the pressure or not we don't know, but it was put down as a one off because that's the way they prefer to deal with things.*
	Illness masked	• Misattribution - credit crunch • Ill for a long time • Negative rather than positive symptoms	*T: And then, what didn't help is when he got out of Uni, the credit crunch. No work, he was trying to be a graphic designer, and people want you to work for nothing, the whole lot was rubbish, and he went for several years trying to get work, which was quite depressing, so his illness was probably a bit masked, cus you couldn't see what was going on. And that probably went on for about five years didn't it? [D: Yea.] You were a bit flat and you're enthusiasm was not there. It sort of grew on him, it crawled behind him and took him down, and then you don't understand what's the problem.*
	Impact on work	• Symptoms impacting ability to work	*D: I'd say the second lot of being unwell, was when I was 25, and my head just went kinda numb, I struggled to think straight on this side of my head. And then that led to me not doing very well at work. I got jobs but they were lower jobs that what I was qualified for. So I struggled and then ended up having to leave the supermarket because I was too fatigued.*
	Response to symptoms	• Knowing help needed, but not sure what's going on • Trying to help himself	*T: That was difficult, because, he was in need of help really, but we didn't know how to help him cus we weren't sure what's going on, Cus at the start, he was*

		• Parents noticing bizarre behaviour	*trying to make himself better, you said that didn't you? Looking on the internet, and he was eating hundreds of oranges at one time, juicing them up.*
Past: Journey into Services	Unsuccessful help-seeking	• Being made to wait for referral • Continued help-seeking from Dr with no help • Should have gone to A&E	*T: When you get to the doctors, they just refer you to somebody else. The most upsetting part was, when we knew there was a big problem, we went to the doctors, and they put you off by sending a letter to someone and else and they say come in six weeks. When we got there, the specialist guy said he wanted a longer meeting a put it off for another six weeks! That was really a killer wasn't it? [K: yea], cus we thought "we're getting some help", after going along with every day like a nightmare to him, it's like him lying in the road with a car accident, he should've been in hospital.*
	Uncertainty over what services accessed	Disagreement within family as to whether they went to A&E	*D: I did go to A&E* *T: Not that time you didn't.* *K: The first one when you had the psychosis, dad took you.* *D: No I thought I went to A&E and the Dr wouldn't see me either.* *K: I don't know* *D: I did.*

	Getting somewhere with services	• Watershed moment - led to EI team	*T:You felt as if you're getting somewhere, which is good. The best thing, we had a big watershed. We went from being left out in the cold, the road accident feeling that you're on your own, for months, to...he got admitted to hospital didn't he? ...We went from 'we don't care about you, go away for 6 weeks', to 'we can do everything for you.'*
Past: Doing BFT	Useful aspects of the BFT	• Contact with EI team • Family meeting • Relating back to strategies & using handouts • Eye contact one helped • Organised what we've got	*T: We find it useful in the sense that it's contact with the EI team as well.* *K: I found it useful. She gave us things to do and one was a family meeting on a Sunday night, that's very useful.* *-----* *T: All these headings, problem solving, goal achievement, active listening, making positive request, expressing your feelings, every one of those statements we can relate back to if we needed to couldn't we?*
	More useful for parents than Dave	• A few things useful • Disappointment • Wanted it to increase parent's understanding, but it didn't • Confusion over role of clinician, due to dual role • Parents disagreeing over the point of the BFT	*D: The family therapy has been useful, a few things have been useful, but I think it's mostly useful for my parents...I feel a little bit disappointed. But my parents have enjoyed it. I thought it would help my parents understand more about what's wrong with me, than it has, but they find it difficult to understand, that's why I did it, I asked to do it. But I still end up having to explain myself a lot.*

Present: Working with the EI Team	Continuity of care	Not having to re-explain yourself	*T: The worst thing, in our position is having to re-explain yourself, even Dave says this. You get fed up of saying the same things. But if you know somebody knows you, you just say 'he's been better than last time', and that's good enough.*
	Aspects helpful	• Good to be with others who are ill - social • Seeing the staff - space to talk	*D: Going to the drop in centre, that's been really good. It's different cus the people there aren't suffering in the same way as I am, they have voices, which I don't get that side in the same way, and they get delusions, but they are still ill people, so it's nice to have something in common, and also there's social workers there, and care staff, so I get to talk to them. And the Dr's there as well, I've seen her a few times, and the psychologist.*
Broad Aspect: Diagnosis	Impact of schizophrenia diagnosis	• Everything is explained by it • Mother also has diagnosis	*T: It's such a big title that anything goes in it. If you've got a bad foot, "what do you expect?". If you've got a noise in your head "what do you expect".*
	Disagreement over diagnosis	• With the service • Within the family - dad thinks Chronic Fatigue Syndrome & Dave doesn't think he has psychosis / schizophrenia	*D: There's a bit of a disagreement between me and the doctors, cus I feel like it's more physical, this pain, but they're telling me it's a mental issue. Hallucinations they call it.* *T: The biggest problem is, I'm the only person who's said this, and nobody's listening, is that he suffers from CFS. This is fatigue.*

	Disagreements about medication	• Disagreement between Dave and Drs, and Dave and family.	*T: He doesn't always agree with everything. He's the one taking the tablets, he doesn't always see what position he's in himself and he can't always see the point in it. You get to the stage where you don't want to take the tablets don't you? And we know it's a disaster to stop taking them. He'd probably still do it now if he was on his own.* *D: Yea I would.* *T: But that's not right, you're not gonna be any better.*
Present: How Things are Now	Monitoring symptoms	Still has symptoms	*K: And he gets a really good day, not a lot of good days, but he doesn't know why, and then he starts to function, thinking I'm doing things, and then the next day he's back to, how you are aren't you?* *D: Yea* *K: And he keeps a chart, how he is every day, and scores it.*
	Family roles	• Disagreement about relationships • Dad as carer involved in all appointments, as Dave not well enough	*T: We aren't a family that are distant from each other cus we all live in the same house anyway, we don't fall out, we try to help each other.* *D: We are falling out more recently. It's difficult though when you're unwell.* *-----* *T: I've sat by his side, and I won't stand anything from*

			any doctor that tells me "I'll talk to him first". "Sorry you won't. I'm his carer I sit next to him. I want to know what you say and I want to know what he says". *D: If I was well enough I wouldn't have my dad there, but cus I'm not well enough my dad has to be there. Cus I need the support.*
	Not getting better	• Going backwards • Being stuck • No independence • Feeling different to others with psychosis • Frustrating	*T: It's ruining his life cus he hasn't got a life, have you?* *D: Not at times, no.* *T: He hasn't got a life outside his bedroom. This is as far as he gets on his own. He's stuck.* *D: I don't feel like I've got that much better, that's a bit frustrating.*
Future	Urgency to find more help		*K: We're in a hurry now, cus it's ending, the early intervention.*
	Parental fear of going back		*T: He'll end up going back in his box and start living in a world of your own and then you'll end up in a hospital bed again.*

Family 4

Phase	Subplot	Theme	Examples
Past: Before Help Obtained / Being Ill	Illness as a shock & unexpected	• Nothing wrong before illness • Ruined life	*H: Before Gemma was ill, there was nothing wrong!* *G: We never expected that it would happen, both times.* *H: The first time was a massive shock to me, as the second time was even more of a shock.*
	Response to symptoms	• Gemma trying to convince mom of illness - misattribution to teenage behaviour • Worry re: bipolar • Taking professionals' word for it	*G: The first time I knew myself didn't I? But I couldn't convince you that there was something wrong, which was hard. I kept telling didn't I, that I was down and didn't want to go to college, different things, and you just thought that...* *H: I just thought it was normal teenage problems, I could relate it to when I was her age, and it wasn't until, when she started saying things, and I though "it hasn't happened, it's in her mind, it hasn't happened", but by that time it was kind of...* *-----* *G: I used to say to you at times that I thought I might be bi-polar didn't I? [H: Yea you did yea.] I used to look at it on the internet, what it was.* *H: She did, yea, at the end of that period, I remember coming home one night and she said "mom I think I'm bi-polar" and at this point I'd asked them and they'd said "no", I thought "well they're qualified, so I can*

			take their word for it", and I said "no, they said you're not dear, but ask the question again."
	Relationship with work	• Work supportive	*H: Yea you did have support off the manager at the hotel, he was very good with you.* *G: He was, cus really I should have lost my job [H: yea] with what I was doing. He was very good with me.* *H: He kept having you back, didn't he?*
Past: Journey into Services	Accessing EI team	• Hoping to be accepted by EI • Seeing the right people happened quite well	*H: I think although Gemma was taken into hospital the first time, she was assessed, it did all move along quite well didn't it as to [G: yea] seeing the right people.*
Broad Aspect: Wider Support from EI	Social activities & making friends, getting work	• Social activities leading to making friends • Helpful being with others who've been through similar	*G: I've met my closest friends at the minute through that, so that was nice.* *H: I suppose it's good to meet people who've had similar...* *G: Been through the same thing...*
	Benefits of EI support	• 'lots of help' • Getting apprenticeship • Knowing someone's there - can talk to clinician	*G: I pretty much got my job through EI as well didn't I? [H: yea] I'm about to start an apprenticeship, so I got that through them.* *H: The apprenticeship, you wouldn't have got that.* *G: No, there's a lot of things I wouldn't have got, or wouldn't have done isn't there? [H: mmm], they've been a big help.*

	Individual support for Gemma	• Importance of individual work also	*H: Yea I don't think I should always be there because it is important she gets on with Emma so she can talk to her and discuss things with her when I'm not here, I think that's important as well. And with Emily {psychologist} as well.*
Past: Doing BFT	Being OK in some areas already	• Did things naturally, didn't have a problem	*H: Emma said on communication, problem solving, that we hadn't really got a problem with that, because she said we do it naturally.*
	Finding aspects hard	• Upsetting to go over what happened • Awkward doing role plays • Hard aspects still helpful	*H: We both said after that, that was quite depressing wasn't it [G: yea] cus it was upsetting. You think you've moved on and you have to go back and talk about it again, it was, depressing.* *G: Bringing it all back up again. We had to go back to it and relive it, wasn't it? That wasn't nice. It was good though, to go through it [H: yea], the problem.* *H: I suppose it's therapeutic to talk to someone, talk through it.*

	Helpful aspects of the BFT	• Early warning signs • Equal focus on mom & daughter • Learning 'sticks in mind' during situations • The sheets given	*H: What was helpful, Emma gave us, well you had it...* *G: yea, it was really helpful. The sheet? [H: yea] She typed up a sheet with early warning signs, triggers, what to do in an emergency, what tablets to take, which is really helpful, it's really good. She obviously spent a lot of time doing that. Just knowing that it's there, and it was helpful to read it, wasn't it? [H: yea].* *-----* *H: And the things that she did, it sticks in your mind. [G: what's that?] Say I think things to myself sometimes, and I think "oh I shouldn't think it to myself, I should say it".*
	Impact and benefit for family	Good that it's for family	*H: It was definitely helpful for me to be involved in the family sessions. I would have felt very much out of it if they'd just done it with Gemma, because obviously it is Gemma that's ill, but it has a big impact on family members as well.*
Broad Aspect: Diagnosis	Suspicions of bipolar	• Asking team if they thought it was bipolar but being told no • Psychologist's suspicions re: bipolar	*H: I think the only thing I'd say was after Gemma had been ill the first time, which was in September 2012 [G: yea], the next year, the way she was behaving, I didn't think it was in character and I did phone them up them a couple of times and asked Dr Brown when he came out, asked if they thought she was bi-polar, and they said no.*

			G: And even the psychologist I was seeing at the time [H: yea], she even said to me that she thought I was bi-polar. *H: Yea, I didn't know that, she said you'd got bi-polar tendencies.*
	Alternative what if story	• Could second episode have been prevented? • Ruined life and plans • Impact of incorrect medication	*H: It still makes me think, what if? If she was on the wrong medication, and if she'd have had a different medication, would it have prevented that happening? [G: Yea] Because this was massive, what happened to her, like you said didn't you, it ruined her life, it ruined her plans. And I know we can't say it never wouldn't have happened but you just think, what if?*
	Benefits of diagnosis	• Not nice, but nice knowing it's something • Preferable to just episodes of psychosis • Being put on right tablets	*G: It wasn't nice but I suppose it was nicer to have a diagnosis and not just think that it's just episodes of psychosis, that would keep reoccurring. It's nice to know that it is bipolar, it is something. And also it's nice to have the diagnosis to be put on the right tablets, which is good. That changed, didn't it? [H: yea, big time] That was helpful wasn't it? [H: yea]*
Present: What Things are like Now	Noticing improvement as recovery	• Getting out more, helped by friends made through EI	*G: I've definitely improved since then though. I noticed I was getting a bit better after Christmas, or perhaps just before, Until then things were still quite bad, but the main thing is I was getting out more.* *H: And that was led through by meeting people through...* *G: Yea, through EI, and the friends I made there.*

	Better knowledge of identifying & coping with difficulties	• Being able to explain feelings • To identify problems and get help earlier • For both to do	*G: It's good isn't it, to know that it's bi-polar, cus if there's times when I'm feeling really down or really high, I know...* *H:I think it's really helpful to hopefully now be in a position where you can identify that something's wrong, and get help before it develops hopefully.* *G: What you mean you identify?* *H: Either of us, both, it's you and me isn't it?*
Future	End of EI support	• EI replaced by apprenticeship • Ability to self refer in future • Strange the support not being there	*G: It is a worry isn't it that if something happens, they're not just on the end of the phone [Helen: yea, definitely], you can't just ring somebody. But in a way it's good, cus it's, moving on again. Got to do it some time.* *H: But it's been such a big part of both our lives.* *G: And it will be quite a shame won't it not to see Emma as well [H: yea].*
	Prospect of apprenticeship	• Would share if having problems • Benefit of MH apprenticeship • Hope for job in the future	*G: With my new job, I think I'd tell them if I was having problems, because this apprenticeship is for people that have had mental health problems, so my new manager, she'll be aware of that, and she's also been through problems as well, so I know that I'll be able to talk to her.*

	Thoughts about illness in the future	• Hope nothing further will go wrong (also mentioned in 'end of EI support') • Using what they've learned to prevent future episodes	*H: Yea you just hope that...* *G: Nothing will happen again.* *H: Yea, that you won't need it again anyway.* *G: I hope that it never does happen again, but you can't say, it worries me a lot. Cus it's really not nice, it ruins everything.* *H: I think that there's lessons to be learned that Gemma's got a vulnerability to substance, alcohol, so she's learned that that's a trigger or has been, and if we stay within the boundaries, then it would prevent...* *G: Prevent it being...*

Paper 3

Reflective Review Paper

Reflections on my Journey through Creating this Thesis

Word Count = 6342

Abstract

This paper offers an extended discussion and reflective account of the researcher's journey through this thesis, with an aim of exposing how the researcher's personal narratives impacted the narratives within this thesis. A personal and professional position of social constructionism is presented, demonstrating how this philosophy contributed to the development of the thesis. Aspects of the literature review and empirical research are discussed in turn, elucidating decisions made during the design and implementation of these projects. Further discussion points arising from these two papers are also presented. Reflexive considerations, and the limitations and value of this thesis are presented. Final reflections highlight the researcher's personal learning during this process, and bring this journey to a close.

Introduction

The previous two papers presented different but complementary stories. The literature review presented the story of the research literature on help-seeking following a first episode of psychosis (FEP), and the empirical research paper presented the story of families who were completing Behavioural Family Therapy (BFT) following FEP. This final paper presents my story as a researcher creating a thesis on family narratives. This is my journey, and as such is written in the first person when appropriate.

The Beginning of my Journey

Inspiration for this thesis came from a fact learned early on in my training; that 45% of those diagnosed with schizophrenia recover (Barbato, 1998). This differs starkly from original views of schizophrenia as a longstanding degenerative disorder; I had previously read with interest Laing's (1960) critical observations of schizophrenia. The move towards identifying and treating psychosis rather than schizophrenia contributes to ideas of recovery in this area; indeed, psychosis is now defined as a common human experience (Cooke, 2014). I wanted to explore the journey of recovery, or otherwise, in those who had experienced psychosis, as recovery seems a relatively recent idea in psychosis and schizophrenia. The concept of shared family narratives emerged following discussions with clinicians working with clients experiencing FEP.

Epistemological Position

While professional interest inspired my research topic, personal experiences influenced my epistemological position. I grew up being encouraged to critically engage with my world, from questioning truths as represented in the media, to exploring the diversity of human experience, through my father's tales of travelling the world. In education I sought to expand on this approach through studying and applying philosophy whenever possible. I first learned

of narrative approaches as a postgraduate, building upon this knowledge during my present training.

These experiences contributed to my social constructionist worldview. Social constructionism rejects notions of objective 'truths', positing that knowledge and truth is actively constructed through our social interactions with the world and each other (Burr, 2003). Shotter (2000) describes a conversational approach to social constructionism, which focuses on people's responsive understanding of one another, embedding constructions within their context. Narrative research incorporates such ideas, assuming the world is actively constructed through narratives (Sarbin, 1986), and taking a contextual approach to exploring individual experience (Clandinin & Connelly, 2000).

The Literature Search

Database searching.

An initial broad scoping search for literature on experiences and help-seeking in FEP revealed a wealth of literature on the duration of untreated psychosis (DUP) and delays to help-seeking, but less on experiences of active help-seeking. The literature on the former two areas was too large to review succinctly, and as there was less on the latter, this area seemed worth exploring further.

During scrutiny, some papers' titles suggested they were relevant to the search question; however on further scrutiny, these did not focus sufficiently on experiences of active help-seeking. For other papers the converse was the case, causing concern that some rich information may have been missed during scrutiny of titles and abstracts. However, two review papers on carer experiences were used (Cairns, Reid, & Murray, 2014; Dawson, Jordan, & Attard, 2013) to validate and cross check the papers included and excluded for review. This was only possible for studies regarding carers' experiences; however papers exploring individuals' experiences were scrutinised thoroughly, due to an awareness that these were underrepresented in the overall search results.

Hand searching.

Initial literature searches involved an evolving process of searching and scrutinising the literature, and updating search terms in light of relevant hand searched papers missed by database searches. The three papers eventually obtained only through hand searching contained search terms within all four 'clusters' of those used in the final literature search (see Appendix A.2). Failure to uncover these through database searching was therefore not due to omission of key search terms. The publication of these papers account for their absence in the databases searched - one was an unpublished thesis, one was published in a database of systematic reviews, and one was not yet indexed by the databases searched.

The Methodological Critique

Several ways of presenting a critique of the literature were tried. Initially, each paper's findings and methodology were presented and critiqued individually; however this disintegrated approach did not synthesise the literature. An integrated methodological critique, followed by a synthesised exploration of findings, converged better with the overall thesis of exploring shared narratives in FEP. For readers seeking further information, a table containing a methodological critique of each paper is included in the appendix of the paper. In practice, the integrated approach revealed dominant ideas about the (lack of) importance of reflexivity in published papers as a possible reason for a broad lack of reflexivity within the collective literature. This is an important finding, with implications for future researchers and journal editors.

Choosing a quality assessment measure.

The Critical Appraisal Skills Programme (CASP, 2013) was initially used to critically appraise the quality of the papers, however, Elliott, Fischer and Rennie's (1999) guideline on qualitative research standards was used to enhance this critique, and seemed a more comprehensive model within which to present the integrated methodological critique.

The Synthesis

Some papers selected for synthesis contained findings relating to broader aspects of FEP, which were beyond the scope of the review; therefore only those findings which directly related to active help-seeking experiences were synthesised. The papers presented different aspects of active help-seeking experiences, for individuals, carers, or both. This diversity of different specific time periods and different perspectives within the active help-seeking process enabled a fuller narrative journey to be synthesised.

Extended discussion of the synthesis findings.

Space restrictions prevented an extended discussion within the literature review paper; further relevant discussion points are included below.

A striking finding was the missed opportunities for help. Formal help-seeking at times occurred during the prodromal phase, with individuals and carers aware that something was wrong, though not sure what. Cairns et al. (2014) also described such a period where carers sought answers to make sense of difficulties, within which professionals could be instructive. However, the literature revealed that this help-seeking was at times ineffective, with help only provided once florid psychotic symptoms were present, often culminating in a crisis. Symptoms in the prodromal phase can be difficult to identify (Chiliza, Oosthuizen, & Emsley, 2009), which may explain why both help-seekers and help-providers did not act as efficiently as desirable in retrospect, and why numerous help-seeking attempts may be made prior to a crisis (Johnstone, Crow, Johnson, & MacMillan, 1986; Lincoln, Harrigan, & McGorry, 1998). Health professionals who fail to recognise FEP at this early stage may reinforce misattribution of symptoms, thus deterring future help-seeking efforts (Dawson et al., 2013). This highlights the importance of training for primary health care providers.

Individual differences and contextual considerations.

Findings from a Chinese study (Wong, 2007) implied a clear pathway of help-seeking, which differed from the dominant narrative of help-seeking in the literature. This difference may arise from different service designs, availability and public information campaigns. Birchwood et al. (2013) suggest that the impact of public health campaigns on psychosis in the UK is mediated by health system delays, proposing that service pathways be improved in order to reduce DUP.

The majority of carer participants in the studies were female, while the majority of individual participants were male. This likely reflects that carers are more likely to be female; however, experiences of male carers may be underrepresented in the literature. Future research specifically focusing on male carers' experiences, and those of female individuals, may provide an area for comparison of existing findings.

Limitations of the Literature Review

The varying definitions of FEP were accounted for by including a wide range of terms which ultimately described a first episode of psychosis. However, different uses of this and similar terms may reduce the homogeneity of the participants across the collective literature.

The methodological critique within the paper, while providing an overview of the quality of the overall literature, does not enable comparison of the quality of each paper. The detailed critique table in the appendix attempts to address this.

Finally, as the only researcher involved in selecting and synthesising the literature, my personal and professional bias may have impacted on this process. To counter this as much as possible, inclusion and exclusion criteria were created and followed, and the process and results were cross-checked with my supervisor.

Researching Families' Stories

Designing the Research

My initial aim was to explore the process of recovery for those who had experienced FEP. In order to design a clinically relevant and useful research project, I approached psychologists from several Early Intervention (EI) teams to discuss and refine the research proposal. The psychologist who agreed to support the research worked in a team using BFT; thus I learned of this approach and designed the research to consider journeys of recovery in BFT. As BFT involves family work, and the process of recovery in the context of the family hadn't been explored, this became the research focus.

I soon learned of the Meriden Family Programme (Meriden, 2015), which trains BFT therapists; I made contact with Meriden to advise that I was undertaking research in BFT and subsequently their service user consultant provided advice on increasing the accessibility of the recruitment material.

Choosing a Narrative Approach.

Narrative research is an interdisciplinary approach, which takes stories as an object of investigation (Riessman, 1993). The area is broad, with multiple theoretical and historical influences, and varying terminology (Squire, Andrews, & Tamboukou, 2013). However, narrative analysis enables consideration of context and exploration of a sequence of events; this distinguishes it from other qualitative methods (Cortazzi, 1993), such as phenomenological methods, which often explore phenomenon in the absence of such context. Narrative research is also less prescribed than many other qualitative approaches, as it facilitates the researcher's focus on the structure or content of narratives, or both, depending on their research aims (Riessman, 2008). The adaptability of narrative research to the specific context of its subjects and the specific aims of the research also makes narrative research unique within qualitative methods. A narrative research approach best suited the aims of exploring FEP and BFT as a journey, and in the context of the family, enabling consideration of the process of recovery.

This was a social constructionist approach, due to the emphasis on context and social interaction in the creation of meanings (Dallos & Draper, 2010).

Methodology

Recruitment.

Criterion sampling enabled recruitment of participants meeting specific criteria, in order to obtain a homogeneous sample from which to collect rich narratives on experiences of FEP and BFT.

Number of participants.

When establishing a sample size for qualitative research, there exists a tension between obtaining a breadth or depth of data, which must be resolved through consideration of the research aims (Patton, 2002). The aim of the research was to collect and explore rich narratives of a small number of families, rather than superficially representing a larger amount of data. Therefore, depth over breadth of data was prioritised. I considered how many family interviews I could reasonably conduct, transcribe and analyse, aiming to recruit between five and eight families. Transcribing the family interviews took longer than the average transcription time for individual interviews, due to overlapping speech and identification of different narrators.

Inclusion and exclusion criteria.

Families unable to speak fluent English were excluded from recruitment, as narrative analysis inherently requires a linguistic understanding of the text to be analysed, and unfortunately I only understand English. No families were in fact excluded due to such criteria; there was limited ethnic diversity in the geographical area within which the main trust I recruited from covered.

Difficulties with recruitment.

Unfortunately I faced difficulties with recruiting participants. I originally chose to recruit from two EI teams from one trust, as they delivered BFT to a relatively large number of families. I met with these staff teams, who were enthusiastic and supportive of the research, and confident that 5-8 families

could be recruited in sufficient time. However, despite gaining research approval by May 2014, by the end of that year I had interviewed only one family. Recruitment progress and issues were discussed during monthly team meetings; however the teams had noticed a drop in the number of families agreeing to take part in BFT, or continuing with this past the first few sessions. At times, the teams were also extremely busy, which may have made recruitment a lower priority for clinicians.

In January 2015, I took two steps to improve my chances of recruiting participants. With the help of Meriden, I contacted several more EI teams, and two teams from two separate trusts agreed to help me to recruit. Also, instead of only recruiting families who had completed BFT (with the exception of follow up sessions), recruitment was opened up to families who were still completing BFT, as long as they had begun the therapeutic intervention stage. I quickly obtained the necessary research approvals, optimistic that at least five families would be recruited in sufficient time.

Unfortunately, further challenges arose. Communication with one newly added team was difficult due to the absence of my main contact, with other staff unaware of the research; this resulted in me cold-calling clinicians to no avail. The other newly added team helped me to recruit one family. A second family declined to participate because of concerns about confidentiality which I was unable to address directly, due to not having consent to contact the family. The circumstances for a third family who were to be approached changed, and the clinician decided it was no longer appropriate to approach them. During this time, I recruited two further families from the original teams. Another family declined participation, and a further family agreed to an interview date, but cancelled scheduled interviews three times.

This experience was extremely frustrating. I spent a portion of each weekly study day trying to contact all of the clinicians who may be able to help me recruit for progress updates, which resulted in a mixture of hope and despair each week.

A number of factors may have contributed to the recruitment difficulties. I relied on clinicians to choose which families they approached and when, as they were best placed to judge whether families could tolerate

sharing their experiences. However, this also made clinicians the 'gatekeepers' to participants, which Callard et al. (2014) argue may enable 'medical paternalism' (p. 2), preventing some potential participants from taking part in research. Clinicians can experience time constraints, or may worry about impacting service-user relationships during recruitment (Pringle & Churchill, 1995). Engagement in EI and BFT itself can be difficult for some families (James, Cushway, & Fadden, 2006), thus clinicians may have worried about disrupting tentative relationships through introducing the research. Being unclear of the benefits of the research may also impact clinicians' motivation during recruitment (Bucci et al., 2014). This may have been the case in the two teams added latterly; the initial contacts made in these teams were enthusiastic about the research, however the other clinicians in their team may not have been as motivated to engage with the research.

The lack of my physical presence within teams may have reduced their motivation or awareness of the need to recruit. I attempted to address this through regular telephone and email contact with clinicians, while trying not to 'pester' them. Attendance at team meetings was discussed with with the two newly added teams; however team managers did not provide dates for this. While meeting the teams in the first trust I recruited from proved positive, no further physical meetings were arranged. As a result I was an outsider to the teams, with lack of physical contact hindering opportunities to establish working relationships with clinicians.

The commitment required from families participating in the research may have caused some families to decline, or clinicians to deem this as too inconvenient for them. Approval was obtained for interviews to be conducted at either families' homes or their local EI service, to provide a choice of location. I was also flexible with interview times, however this flexibility was not specified in the participant information; therefore families who worked during the day may have felt unable to participate, or clinicians may have refrained from approaching them for this reason. Further, some families may not have wanted to share their experiences in front of other family members. While I assumed that families who had completed BFT together may be relatively at ease participating in the research together, therapeutic and

research tasks differ, and the ambiguity of the research situation may have deterred some families.

Ethical Issues.

Clinicians were asked to approach families for ethical reasons. Firstly, access to participants' personal identifiable data was not necessary; I only required a contact number if families were interested in the research. Families were therefore initially able to consider participation without the pressure of contact from me as an outside professional. The invitation letter contained an 'opt-in' slip, where participants provided a contact number and consented to being contacted about the research. Secondly, clinicians were asked to consider families' ability to cope with the interview prior to approaching them. All families recruited were open to the EI team, with clinicians available for follow up should families need this.

I obtained informed consent to participate immediately prior to the interview, to ensure participants had time to consider and discuss the research, and ask questions. Having completed the required Good Clinical Practice training, collecting consent myself ensured the quality of this process. Families were informed that the interview could be stopped at any time, and were made aware of their right to withdraw. They were reassured that if they declined to participate or withdrew from the study, this would not impact their care. While no participants were aged under 16, separate information sheets and parental consent forms were available for those under this age. Those under the age of 12 years were excluded, due to the potentially sensitive nature of the interview. Finally, participants were told how they could obtain a summary of the completed study.

Interviewing families.

Shared family narratives were collected through group interviews with families, in order to focus on the community level (Rappaport, 1995) narratives of the family, about their journey through FEP and BFT. This focus on community level family narratives is important, as established theories implicate the family as key in illness and recovery in psychosis and schizophrenia (Brown, Birley, & Wing, 1972; Vaughn & Leff, 1976); therefore such narratives can provide insight into family processes of recovery.

Individual stories differ, as accounts are subjective (Kirkpatrick, 2008), and influenced by what we believe others are prepared to hear (Frank, 2010); narratives co-created in a group setting therefore differ from individual narratives, but are influenced by these. The joint interview process enabled families to jointly tell the story of their journey as a family. In group interviews, the responses given by one participant may prompt responses from another, that would not have be elicited in an individual interview (Seaton, 2008; Sparkes, 2014); this highlights a unique strength of group interviews in eliciting rich and diverse narratives.

Interview questions guided families to describe their experiences as a journey, as exploring families' journeys was a research aim. Examples of these questions are: 'How did you first come to know you needed help?', 'What was doing the BFT like for you as a family?', and 'How are things now?' These questions were kept as broad as possible, to enable families to talk about the aspects of their experiences which were significant for them, within the different phases of their journey. Asking such temporal questions encouraged families to reflect on areas they may not have talked about otherwise. For example, families may not have considered the future if not explicitly asked about this; however the future is an important part of families' journeys in relation to recovery, and their answers to this also reflected their present context.

Sometimes I asked questions about what family members thought of what had been said by another member, if there had been little shared engagement during a particular answer. This was due to an awareness that the children of the family were generally speaking less during the interview. This approach encouraged these individuals to add to the narrative, without guiding what their response would be. Sometimes they agreed; at other times they added to the narrative, and at others they introduced different topics. All of these revealed the shared family narratives.

Following each interview, I made brief notes on the observable level of engagement by family members, such as if and when they nodded when others were speaking, or if they yawned or appeared disengaged. I also noted initial impressions of the interview content, and my questions.

Transcribing.

I transcribed each interview myself, to begin the process of immersion in each family's story. My observations were added to the transcriptions, which was helpful when exploring the extent to which narratives were shared. Detailed transcribing conventions were not necessary, due to an emphasis on the content of families' narratives, rather than how words were spoken. However, overlapping speech was indicated, as often this revealed agreement, or a 'chipping in' to the story. Transcription also revealed the regularity with which common 'superfluous' phrases were used, such as 'you know', or 'like'. The core story process made the content of the narratives much clearer following removal of these words.

My narrative approach.

There is no single definition of narrative, nor a specific formula for conducting narrative research (Brockmeir, 2013; Riessman, 1993) and no rules regarding the best level at which stories should be studied (Squire et al., 2013). However, rather than being a weakness, this may be a strength of narrative research. This flexibility enabled me to design an analysis method which suited the context of the research.

In order to develop my method of narrative analysis, which would explore families' shared narratives of their journey, I read many books and papers on narrative research, and attended conferences and workshops whenever possible. The possibilities for analysis were both exciting and overwhelming. The difficulty faced when designing a valid method of narrative analysis is acknowledged by other researchers (Brockmeir, 2013; Squire, 2013), alongside firm recognition that there will not and should not ever be a definitive formula for this.

Following much research and reflection, and some trial and error, I gradually selected the analysis approach which best suited the research aims. Part of this process included practising using certain analysis methods with sections of the transcripts, and exploring what this produced - considering the extent to which the journey and shared family context was revealed, and discussing this with my supervisor, who has experience in narrative analysis. I established that the analysis should focus on the content

of each family's narratives, rather than the structure, as a thematic focus is helpful when looking at the commonalities between a number of interviews (King & Horrocks, 2010). The entire interview response can be defined as a narrative (Gee, 1991; Riessman, 1993), therefore families' overall interview responses were accepted as a narrative of their journey through FEP and BFT. Structural definitions of narrative, such as Labov's (1972) were not appropriate, as these do not allow for events which extend over time and into the present to be classified as narratives (Riessman, 1993).

As the research explored shared family narratives, Rappaport's (1995) levels of narrative model was used to elucidate community level family narratives. Analysis involved both a description of families' stories, as restoried by me to highlight the temporal phases of their journey, and exploration of the subplots and themes which emerged from these stories (Creswell, 2012; Ollerenshaw & Creswell, 2002).

A novel approach.

Using a similar approach to collecting community narratives from groups of eighth graders, Seaton (2008) describes narrative group interviews as being like a focus group, with less focus. She explains that such an approach elicits a different, collective narrative, rather than individual narratives. This highlights how people's context structures how they choose to express themselves, and the reality they then present (Shotter, 2000).

Such an approach is relatively new within narrative research (C. Squire, personal communication, February 2, 2015), and may represent the next step in increasing context further in narrative research; as narrative analysis provides a context which may be lacking in other qualitative methods, analysis of shared narratives may provide a further level of context unobtainable from individual narratives. In paper 1, research findings of individual interviews were synthesised to consider the possible shared experiences within families seeking help following FEP; however exploring shared narratives through group interviews in my empirical research enabled shared experiences to be directly explored.

The core story.

The first stage of analysis involved creating a core story from each full interview transcript, over a number of steps. Emden's (1998) core story approach involves removing extraneous terms and speech; as the researcher, I was to make the judgement of what was extraneous. I therefore chose to leave in utterances which indicated shared family narratives, through the interaction of the narration.

I chose not to return the core stories to the families to check for accuracy, as Emden does, as these represented families' stories shared during the interview, which was a particular context, with me included as the researcher. Perceptions of the past changes over time and context (Riessman, 2008), therefore families' perception of their core story's accuracy would be influenced by the different context in which they checked the story - as text, read as individuals rather than as a family, and at a different time. Any changes made would change the story 'as told' during the interview (Holloway & Freshwater, 2007).

As families were guided to explore the journey of their experience, their narratives contained temporal phases, which were ordered chronologically when creating their core story, to elucidate this journey. This also enabled consideration of the extent to which the narratives could be evidence of effective BFT; with comparison of families' narratives across each temporal phase.

While ordering families' core stories into temporal phases, I tried to stay true to each family's narrative, rather than imposing exactly the same phases for all families. At times, it was more appropriate to represent a narrative within a 'broad aspect' category rather than a temporal phase, in order to retain the context of the narrative. For example, some families spoke about diagnosis, which incorporated the past, present, and future; however these narratives needed to remain whole to prevent them from becoming fragmented and meaningless sections of text.

Identifying family narratives.

Three of the families interviewed expressed shared narratives during the majority of the interview, based on my approach to identifying these.

Individual narratives were occasionally expressed, which did not incorporate the perspectives of others, and were not enhanced by the contribution of others, however these were minimal, possibly due to my questions relating to how things were experienced as a family.

Bohanek, Marin, Fivush and Duke (2006), following a study of parent-adolescent narrative interaction, described three styles of family narrative interaction. Those adopting a coordinated perspective constructed a shared understanding, created through integration of different perspectives or interwoven narratives (Fivush, 2008). An individual perspective style of family interaction involved sharing of individual narratives without these being integrated into a shared family story, and a final imposed perspective style related to one parent dominating the interaction, while ignoring the perspectives of others. During my interviews, while parents spoke more than their children, the overall family narrative interaction style involved a coordinated perspective, with the exception of one family.

In their study, Bohanek et al. (2006) found that parental acknowledgement and incorporation of adolescents' perspectives enabled a coordinated perspective to emerge. This suggests that even when adolescents spoke less than their parents, this coordinated perspective was possible. In contrast, the majority of one family's interview response contained discordant individual narratives, with only occasional shared narratives. This was quite striking during the interview itself, and made me more conscious of how I worded questions to encourage responses which represented the whole family. However, people will share the stories they want to be heard (Frank, 1995), and this family's narrative was dominated by an individual parental narrative of dissatisfaction with services, which left less space for other, shared family narratives to emerge. However, the contrast with other families' narratives, in conjunction with the contrast in progress made, enabled consideration of narratives as evidence.

Reflexivity

Reflexivity is an important aspect of social constructionist approaches to research, involving consideration of the researcher's contribution to the meanings constructed throughout the research (King & Horrocks, 2010). Just as context is important in narrative research, consideration of the context of the research itself enables reflexivity regarding my role in the creation and interpretation of each family's narratives.

The narratives families shared were created within the context of their family and relationships, but were also created in the context of the interview, with me present as a researcher and listener. Narrative interviewing should free participants to share their own stories, through an unstructured approach (Riessman, 2008); however families were guided to describe their experiences as a journey, through prompting if they hadn't touched on a certain phase of the journey I was aiming to capture. This encouraged a temporal narration of their experiences, which was enhanced during creation of the core story. Western narratives are often temporally structured, therefore this felt like a natural way to explore families' journeys. Temporal guides were kept intentionally broad, with families choosing how much and what they said about each aspect of their journey.

The focus on community level family narratives meant that during the interview family members were encouraged to share how they all experienced certain aspects of their journeys, with questions such as "what was that like for you all?" rather than "what was that like for you?" Such questions encouraged answers representing the whole family's experiences; something which parents may have felt more empowered and comfortable to do. The shared version of families' journeys will differ from purely individual narratives, and the stories revealed reflect only one of many potential versions of each family's experiences of the FEP and BFT.

The stories I created, and my interpretations of these, represent my story of the families' stories (Riessman, 2008). I could only hear, relate, and analyse the families' stories as an observer and outsider; I analysed the stories through the eyes of a psychologist. This professional position, along with a personal optimistic stance may have encouraged my search for a

recovery narrative within the narratives, and the contrasting narrative of one family reminded me that intervention isn't always as effective as would be hoped.

My position as an outsider and professional also likely influenced families' responses. The researcher role aligned more closely with that of the clinicians delivering BFT, than with a lay person or friend role. Therefore, the narratives created in the interview context may reflect those present in the context of the BFT sessions. One way to ascertain this would be to gain feedback from families' clinicians regarding the narratives. However clinicians as another 'listener' would have affected families' narrative accounts; instead, responses remained anonymous.

My interpretations are informed by my subjectivity, comprised of personal and professional experiences and perspectives. Interpretations were informed by a search for a collective narrative account of families' journeys. A different research focus, such as one specifically regarding power, or one about the construction of narratives, would produce different findings accordingly.

Rigour

There is no set method for assessing rigour in qualitative research, and scholars argue that it is inappropriate to use tools which have been developed to assess rigour in quantitative methods (Guba & Lincoln, 2005). Indeed, as methods for narrative research are not set (Riessman, 2008), defining specific criteria to assess validity is difficult. Narrative analysis' adaptability to suit specific research aims and context suggests a dedication to rigour, which cannot be defined or measured by a set criteria. Sparkes (2014) advises that a consistent researcher position increases rigour; thus attempts were made to incorporate social-constructionist assumptions throughout this thesis, from the choice of topic and review of the literature, to the methodology, analysis, discussion, and reflections.

Rather than testing validity, considering trustworthiness can provide a measure of rigour in qualitative research. This, at its simplest means that a methodical approach has been taken, guided by ethical and theoretical

considerations, and the stories of real people (Riessman, 2008). I have attempted to demonstrate my efforts to conduct a trustworthy piece of research in several ways:

- Through providing a detailed explanation of the design of the analysis approach, and how analysis was conducted.
- Through using quotations to support findings, and providing details of all subplots for each family, with further quotations, within an appendix.
- Through linking findings to each family.
- Through detailing ethical considerations and explaining where these guided decisions, particularly during recruitment.
- Through reflecting on the impact of my role on the research, and on the research findings.

Further, some quality checks were applied during the research, through discussing the method and findings with my supervisor who is experienced in narrative analysis, through checking findings against my initial impressions following interviews, to ensure that findings were true to families' stories as told, and through gaining feedback on findings from a professional working within an EI service. The pragmatic value of research is also important (Riessman, 2008) - I discuss clinical and research implications of the findings in the research paper, and hope that I have done justice to the stories families shared with me.

Limitations of the Empirical Research

I eventually interviewed four families; one family below my target. While disappointing, I appreciated the rich narratives these families provided, and found that there was plenty of rich data to analyse, possibly due to the group interview approach (in total, there were ten participants). Narrative research is suited to capturing detailed stories about a small number of individuals (Creswell, 2012), therefore the small sample size is unlikely to have affected the utility of the method employed.

The small sample size prevents any firm conclusions on the extent to which narratives can provide evidence of effective BFT. However, the journeys of these four families alone demonstrate the diversity of experiences of FEP, diagnosis, and BFT. This emphasises the need for BFT to be adapted to suit each families' needs.

It is disappointing that I was not able to interview more families, as this is a rich and important area to explore, particularly due to difficulties in recruitment. On reflection, I may have benefitted from recruiting from more teams from the beginning - this would have allowed more time to develop better relationships with more teams, and provided a longer recruitment period in some.

I initially wondered about the impact of diagnosis on the homogeneity of the sample, which is often desirable in qualitative methods. However, I did not exclude those with a diagnosis, and found that those families with this experience enriched the overall data, and inspired consideration of areas I hadn't anticipated, such as the impact of having a diagnosis.

Often during narrative research, researchers spend lengthy periods of time with their participants, returning to them several times, and establishing a detailed understanding of their lives (Clandinin & Connelly, 2000). This was not possible within the time constraints of my training, and the single interview with each family only captured a limited amount of data, compared to that captured during some narrative research.

Reflections on Ending my Journey

Aspects of my journey through researching and writing a thesis were extremely challenging. In order to ensure my research would be of value, I took time to consider the options when designing the empirical research and literature review. The encouragement of my clinical thesis supervisor was helpful during this time, who assured me that the research would be valuable for the EI teams and their clients. The recruitment difficulties proved very challenging and frustrating; however the interviews were an enjoyable and fascinating experience. I was humbled by families being so welcoming and open, and hadn't expected the level of their interest in my research and training, and their enthusiasm for their stories helping other families just beginning on their journey of FEP.

Writing this thesis was a deeply interesting experience. I enjoyed reading about the endless possibilities and applications of narrative research, and met some very creative and inspiring researchers. The process of transcription and analysis was a satisfying and immersive experience.

During completion of the research, I undertook a systemic family therapy placement, and have reflected on the differences between systemic and behavioural approaches to family therapy. As a social-constructionist, I feel more affinity with second generation systemic practice over more structured programmes, such as BFT. However, researching the area and speaking to both clinicians and families who had experienced BFT widened my perspectives regarding structured family therapy, and it is clear that this is beneficial for many.

Conclusions

This reflective paper has offered an extended exploration and reflexive critique of the literature review and empirical research. I have explored how my own epistemological position contributed to

the overall thesis, considered the decisions I made based on this, explored some aspects of the findings in greater depth, and reflected upon the limitations and value of this thesis, for services, service users, and their families. A final reflection on the overall challenges and what I have learned brings this part of my journey to a close.

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Appendices C: Main Appendices

Appendix C.1: Independent Peer Review Approval

Keele University

RESEARCH AND ENTERPRISE SERVICES

11 December 2013

Rachael Edge
Professional Doctorate,
Faculty of Health Sciences - Science Centre,
Staffordshire University,
Leek Road,
Stoke-on-Trent, ST4 2DF

Dear Rachael

Journeys into Recovery: Family Narratives of First Episode Psychosis and Behavioural Family Therapy

The above project has received final approval from the Independent Peer Review Committee and is permitted to progress for ethical review. Please find attached the peer review comments and accompanying letter for the above project. LREC requests that all peer review proforma/s are sent along with your LREC application form.

Although this project has been deemed appropriate based on scientific merit, you may wish to incorporate the reviewer's constructive comments to strengthen your protocol.

Management approval

You should arrange for all relevant NHS care organisations to be notified that the research will be taking place, and provide a copy of the REC application, the protocol and this letter.
All researchers and research collaborators who will be participating in the research must obtain management approval from the relevant care organisation before commencing any research procedures. Where a substantive contract is not held with the care organisation, it may be necessary for an honorary contract to be issued before approval for the research can be given.

Clinical trial of a medicinal product

Please remember that, if your project is a clinical trial of a medicinal product, MHRA approval is required. You must submit a request for a clinical trial authorisation under the Medicines for Human Use (Clinical Trials) Regulations 2004. Further details can be found at
http://www.mhra.gov.uk/home/groups/l-unit1/documents/websiteresources/con2022633.pdf

If you have any queries, please do not hesitate to contact Nicola Leighton on 01782 733306.

Yours sincerely

pp N. Leighton

Professor A A Fryer
Chair – Independent Peer Review Committee

CC R&D Office, Worcestershire Health & Care NHS Trust

Keele University

RESEARCH AND ENTERPRISE SERVICES

Chair
NHS Research Ethics Committee

Dear Sir/Madam

PI **Rachael Edge**
Title **Journeys Into Recovery: Family Narratives of First Episode Psychosis and Behavioural Family Therapy**

Please find attached the peer review of the above project.

The Independent Peer Review Committee has graded this project at level 1 and therefore can proceed for ethical review without any revision.

We have informed the applicant that although this project has been deemed appropriate based on scientific merit, they wish to incorporate the reviewer's constructive comments to strengthen their protocol.

We have also stressed to the applicant that the Independent Peer Review Committee is NOT linked to or a Sub-Committee of the Local Research Ethics Committee and that you may identify eth cal issues of your own.

Yours sincerely

pp

Professor A A Fryer
Chair - Independent Peer Review Committee

Enc

PEER REVIEWER'S PROFORMA

Research Project Details	
Project title	**Journeys into Recovery: Family Narratives of First Episode Psychosis and Behavioural Family Therapy**
Name of principal investigator	Rachael Edge
Institution of principal investigator	DClinPsy Student Keele/Staffs University

The important or relevance of the problem to be addressed in relation to either or both of:

a) The particular field of research as a whole
There is obviously an identified need for research of this nature in this area of health care

b) The value of this research for health or social care
Although targeted at first case psychosis and the therapeutic management of this, this could be applicable to any person with a long term condition where the psychological aspect of care is still neglected and inadequate. This research may provide an approach which could be utilised for this large group of patients. A very worthy area of research

The quality and relevance of the background information provided

Very clear and explained the need and justification of the study well

Design, methods and strengths and weakness of the proposed plan of investigation

The study methodology and methods were clearly written and easy to understand. They were justified and fit for purpose to answer the research question posed. Clear and appropriate inclusion and exclusion criteria

The quality of analysis provided (statistical or qualitative, as appropriate)

Again clear and appropriate methods of analysis outlined

The capacity and expertise of the research team in the context of the proposed study
The capacity and expertise of the research team supporting this student is unquestionable and will ensure excellent standards and success

Appropriateness of resource requirements
No problems identified

General feedback (indicate major areas where changes will be required, indicate whether any weaknesses indicated in any of the above categories are major or minor areas of concern)
This is a very important area to research which could have implications for the wider health care system and not just mental health. People with long term conditions who often suffer psychological problems could access such therapies if proven to be successful. It is a very well presented and articulated proposal and I would be interested to know the outcomes of the study and how it will be implemented into clinical practice

Assessment of Merit

Grade	Description	Pls tick
1	Proceed without any revision. Project may be submitted for appropriate NHS/University approval and then to either the Local or the Multi Centre Research Ethics Committee.	X
2	Minor amendments or Further information required. Revise project according to reviewer(s) recommendations. Document to be checked by Internal Committee Member prior to Chairman's approval to proceed.	
3	Complete major revision required. Principal Investigator to discuss outcome with Centre/Programme Director and agree plan to complete substantive revision of the project (with support as agreed). Resubmission will need to be reviewed and approved by Internal Committee Member, prior to Chairman's approval to proceed.	
4	Reject on the basis that the project has major scientific flaws	

Appendix C2: Research Ethics Committee Proportionate Review Approval

Part of the research infrastructure for Wales funded by the National Institute for Social Care and Health Research, Welsh Government.
Yn rhan o seilwaith ymchwil Cymru a ariannir gan y Sefydliad Cenedlaethol ar gyfer Ymchwil Gofal Cymdeithasol ac Iechyd, Llywodraeth Cymru

NISCHR
Gwasanaeth Moeseg Ymchwil | RES | Research Ethics Service

WALES REC 7
PO Box 108
Building 1
Jobswell Road
St David's Park
Carmarthen SA31 3WY
(for sat nav/courier purposes SA31 3HB)

Telephone : 01267 225045
E-mail : sue.byng@wales.nhs.uk
Website : www.hra.nhs.uk

Miss Rachael Edge
Clinical Psychology Professional Doctorate, Faculty of Health Sciences,
Science Centre
Staffordshire University,
Leek Road
Stoke on Trent
ST4 2DF

22 April 2014

Dear Miss Edge

Study title:	**Journeys into Recovery: Family Narratives of First Episode Psychosis and Behavioural Family Therapy**
REC reference:	**14/WA/0127**
Protocol number:	**N/A**
IRAS project ID:	**147519**

Thank you for your email of 15 April 2014, responding to the Proportionate Review Sub-Committee's request for clarifications and changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the sub-committee.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator Ms Sue Byng, sue.byng@wales.nhs.uk.

Confirmation of ethical opinion

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

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

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

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

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The documents reviewed and approved by the Committee are:

Document	*Version*	*Date*
Covering Letter		15 April 2014
Evidence of insurance or indemnity		23 July 2013
Interview Schedules/Topic Guides	1	13 February 2014
Investigator CV		28 March 2014
Letter of Invitation to participant	1	13 February 2014
Demographic Information Sheet	1	13 February 2014
Pre-screen log	1	13 February 2014
Assessment of Capacity to Consent Guide	1	13 February 2014
Email providing clarification regarding personal safety of the researcher		15 April 2014
Participant Consent Form	3	14 April 2014
Parental Consent Form	1	14 April 2014
Participant Information Sheet: for young people under 16	1	14 April 2014
Participant Information Sheet	3	14 April 2014
Protocol	2	14 April 2014
REC application	1	28 March 2014
Referees or other scientific critique report		11 December 2013
Summary/Synopsis	1	13 February 2014

Statement of compliance

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

After ethical review

Reporting requirements

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

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

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

Feedback

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

Further information is available at National Research Ethics Service website > After Review

14/WA/0127	**Please quote this number on all correspondence**

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

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

Yours sincerely

Sue Bygg

Dr Gareth Davies
Chair

Enclosures: *"After ethical review – guidance for researchers"*

Copy to: *Nicola Leighton, Keele University*
NHS Trust

Appendix C.3: NHS Trust Research & Development Approval 1

[redacted] NHS Trust

[redacted]

Rachael Edge
Faculty of Health Sciences - Science Centre
Staffordshire University
Leek Road
Stoke-on-Trent
ST4 2DF

Our Ref: **14_124_NP**

12 May 2014

Dear Rachael,

Thank you for your research application entitled **Journeys into Recovery: Family Narratives of First Episode Psychosis and Behavioural Family**.

I take great pleasure in informing you that your application has been granted approval by the Research and Development Group, on behalf of [redacted] NHS Trust on 9 May 2014.

Please accept this letter as official confirmation of local Trust Approval.

I should like to take this opportunity to wish you well with your research, and look forward to seeing your final report and recommendations.

If I can be of further assistance please do not hesitate to contact me.

Yours sincerely,

[redacted]

Yours sincerely

[redacted]
Audit, Research & Clinical Effectiveness Manager

[redacted]

Appendix C.4: NHS Trust Research & Development Approval 2

[redacted] [redacted] NHS

[redacted]

14 January 2015

Miss Rachael Edge
Clinical Psychology Professional Doctorate
Faculty of Health Sciences
Science Centre
Staffordshire University
Leek Road
Stoke-on-Trent
ST4 2DF

Dear Rachael

Journeys into Recovery: Family Narratives of first Episode Psychosis and Behavioural Family Therapy

Thank you for providing us with the documentation to support your application for R&D approval. We have received notification of a favourable ethical opinion and following a review of all the documentation this study has been approved by the Trust. You may therefore commence the work.

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

In particular, whilst conducting your study you should respect the confidentiality of data obtained from participants.

Please do not hesitate in contacting the Research & Innovation Department should you require any advice or support on any aspect of your project. When contacting us it would be helpful to quote our reference number for this project: **NR1322.**

Yours sincerely

[redacted]

[redacted]

[redacted] [redacted]

Appendix C.5: NHS Trust Research & Development Approval 3

[redacted]

[redacted]

NHS

research & development

[redacted]

[redacted]

Date of NHS Permission: 05/02/2015

Miss Rachael Edge
Clinical Psychology Professional Directorate
Faculty of Health Sciences
Science Centre
Staffordshire University
Leek Road
Stoke on Trent
ST4 2DF

Dear Rachael,

Study Title: Family Narratives: First Episode Psychosis & Behavioural Family Therapy
REC Number: 14/WA/0127
Student Researcher: Rachael Edge
Academic Supervisor: Dr Helena Priest
Service: Early Intervention is Psychosis ([redacted]

Thank you for submitting your project to the [redacted] Trust's R&D Department. The project has now been given NHS permission by:

[redacted] R & D Director, on behalf of [redacted] NHS Trust

NHS permission for the above research has been granted on the basis described in the application form, study protocol and supporting documentation. The following documents were reviewed:

Document	Version	Date
Covering Letter		15 April 2014
Evidence of Insurance or Indemnity		23 July 2013
Interview Schedules/ Topic Guides	1	13 February 2014
Investigator CV		28 March 2014
Letter of Invitation to Participant	1	13 February 2014
Demographic Information Sheet	1	13 February 2014
Pre-screen log	1	13 February 2014
Assessment of Capacity to Consent Guide	1	13 February 2014
Email providing clarification regarding personal safety of the researcher		15 April 2014

[redacted]

Stonewall
MINDFUL EMPLOYER

Participant Consent Form	3	14 April 2014
Parental Consent Form	1	14 April 2014
Participant Information Sheet: for young people under 16	1	14 April 2014
Participant Information Sheet	3	14 April 2014
Protocol	2	14 April 2014
REC Application	1	28 March 2014
Referees or scientific Critique report		11 December 2013
Summary/ Synopsis	1	13 February 2014

Permission is granted on the understanding that the study is conducted in accordance with the Research Governance Framework, ICH GCP [ONLY if applicable], and NHS Trust policies and procedures available ! information/policies-and-procedures/

The research sponsor or the Chief Investigator, or the local Principal Investigator at a research site, may take appropriate urgent safety measures in order to protect research participants against any immediate hazard to their health or safety. The R&D office should be notified that such measures have been taken. The notification should also include the reasons why the measures were taken and the plan for further action. The R&D Office should be notified within the same time frame of notifying the REC and any other regulatory bodies. All amendments (including changes to the local research team) need to be submitted in accordance with guidance in IRAS.

Please note that the NHS organisation is required to monitor research to ensure compliance with the Research Governance Framework and other legal and regulatory requirements. This is achieved by random audit of research.

Yours Sincerely

[redacted]

CC:

Academic Supervisor
Sponsor

Appendix C.6: Author Submission Guidelines for Early Intervention in Psychiatry Journal

Author Guidelines

Manuscripts should be written so that they are intelligible to the professional reader who is not a specialist in the particular field. They should be written in a clear, concise, direct style.

SUBMISSION OF MANUSCRIPTS

• Submissions should be double-spaced.
• All margins should be at least 30 mm.
• All pages should be numbered consecutively in the top right-hand corner, beginning with the title page.
• Do not use Enter at the end of lines within a paragraph.
• Turn the hyphenation option off; include only those hyphens that are essential to the meaning.
• Specify any special characters used to represent non-keyboard characters.
• Take care not to use l (ell) for 1 (one), O (capital o) for 0 (zero) or ß (German esszett) for Greek beta.
• Use a tab, not spaces, to separate data points in tables. If you use a table editor function, ensure that each data point is contained within a unique cell (i.e. do not use carriage returns within cells).

STYLE OF THE MANUSCRIPT

Manuscripts should follow the style of the Vancouver agreement detailed in the International Committee of Medical Journal Editors' revised 'Uniform Requirements for Manuscripts Submitted to Biomedical Journals: Writing and Editing for Biomedical Publication', as presented at http://www.ICMJE.org/.

Spelling. The Journal uses UK spelling and authors should therefore follow the latest edition of the Concise Oxford Dictionary.

Abbreviations. Abbreviations should be used sparingly – only where they ease the reader's task by reducing repetition of long, technical terms. Initially use the word in full, followed by the abbreviation in parentheses. Thereafter use the abbreviation only.

TYPES OF ARTICLES

Reviews which synthesize important information on a topic of general interest to early intervention in psychiatry. (maximum word count for text 5000; abstract 250);

Manuscripts should be presented in the following order: (i) title page, (ii) abstract and key words, (iii) text, (iv) acknowledgements, (v) references, (vi) appendices, (vii) figure legends, (viii) tables (each table complete with title and footnotes) and (ix) figures. Footnotes to the text are not allowed and any

such material should be incorporated into the text as parenthetical matter.

Title page
The title page should contain (i) the title of the paper, (ii) the full names of the authors and (iii) the addresses of the institutions at which the work was carried out together with (iv) the full postal and email address, plus facsimile and telephone numbers, of the author to whom correspondence about the manuscript should be sent. The title should be short, informative and contain the major key words. Do not use abbreviations in the title. A short running title (less than 40 characters) should also be provided.

Abstract and key words
All articles must have a structured abstract that states in 250 words (150 words for Brief Reports) or fewer the purpose, basic procedures, main findings and principal conclusions of the study. Divide the abstract with the headings: Aim, Methods, Results, Conclusions. The abstract should not contain abbreviations or references.

Five key words, for the purposes of indexing, should be supplied below the abstract, in alphabetical order, and should be taken from those recommended by the US National Library of Medicine's Medical Subject Headings (MeSH) browser list.

Text
Authors should use the following subheadings to divide the sections of their manuscript: Introduction, Methods, Results and Discussion.

References
The Vancouver system of referencing should be used. In the text, references should be cited using superscript Arabic numerals in the order in which they appear.

In the reference list, cite the names of all authors when there are six or fewer; when seven or more, list the first three followed by et al. Do not use ibid. or op cit. Reference to unpublished data and personal communications should not appear in the list but should be cited in the text only. All citations mentioned in the text, tables or figures must be listed in the reference list. Names of journals should be abbreviated in the style used in Index Medicus.

Tables
Tables should be self-contained and complement, but not duplicate, information contained in the text. Number tables consecutively in the text in Arabic numerals. Type tables on a separate page with the legend above. Legends should be concise but comprehensive – the table, legend and footnotes must be understandable without reference to the text. Vertical lines should not be used to separate columns. Column headings should be brief, with units of measurement in parentheses; all abbreviations must be defined in footnotes.

Appendix C.7: Author Submission Guidelines for the Journal of Family Psychology

Article Requirements

For general guidelines to style, authors should study articles previously published in the journal.

All manuscripts must include an abstract containing a maximum of 250 words typed on a separate page. After the abstract, please supply up to five keywords or brief phrases.

The manuscript title should be accurate, fully explanatory, and preferably no longer than 12 words. The title should reflect the content and population studied (e.g., "family therapy for depression in children"). If the paper reports a randomized clinical trial, this should be indicated in the title, and the CONSORT criteria must be used for reporting purposes.

Research manuscripts and review and theoretical manuscripts that provide creative and integrative summaries of an area of work relevant to family psychology should not exceed 30–35 pages, all inclusive (including cover page, abstract, text, references, tables, figures), with margins of at least 1 inch on all sides and a standard font (e.g., Times New Roman) of 12 points (no smaller). The entire paper (text, references, tables, figures, etc.,) must be double spaced. References should not exceed 8 pages.

All research involving human participants must describe oversight of the research process by the relevant Institutional Review Boards and should describe consent and assent procedures briefly in the Method section.

It is important to highlight the significance and novel contribution of the work. The translation of research into practice must be evidenced in all manuscripts. Authors should incorporate a meaningful discussion of the clinical and/or policy implications of their work throughout the manuscript, rather than simply providing a separate section for this material.

Manuscript Preparation

Prepare manuscripts according to the *Publication Manual of the American Psychological Association* (6th edition). Manuscripts may be copyedited for bias-free language (see Chapter 3 of the *Publication Manual*).

Review APA's Checklist for Manuscript Submission before submitting your article.

Double-space all copy. Other formatting instructions, as well as instructions on preparing tables, figures, references, metrics, and abstracts, appear in the *Manual*.

Tables

Use Word's Insert Table function when you create tables. Using spaces or tabs in your table will create problems when the table is typeset and may result in errors.

Abstract and Keywords

All manuscripts must include an abstract containing a maximum of 250 words typed on a separate page. After the abstract, please supply up to five keywords or brief phrases.

References

List references in alphabetical order. Each listed reference should be cited in text, and each text citation should be listed in the References section.

Figures

Graphics files are welcome if supplied as Tiff or EPS files. Multipanel figures (i.e., figures with parts labeled a, b, c, d, etc.) should be assembled into one file.

Ethical Principles

It is a violation of APA Ethical Principles to publish "as original data, data that have been previously published" (Standard 8.13).

In addition, APA Ethical Principles specify that "after research results are published, psychologists do not withhold the data on which their conclusions are based from other competent professionals who seek to verify the substantive claims through reanalysis and who intend to use such data only for that purpose, provided that the confidentiality of the participants can be protected and unless legal rights concerning proprietary data preclude their release" (Standard 8.14).

APA expects authors to adhere to these standards. Specifically, APA expects authors to have their data available throughout the editorial review process and for at least 5 years after the date of publication.

The APA Ethics Office provides the full Ethical Principles of Psychologists and Code of Conduct electronically on its website in HTML, PDF, and Word format. You may also request a copy by emailing or calling the APA Ethics Office (202-336-5930). You may also read "Ethical Principles," December 1992, *American Psychologist*, Vol. 47, pp. 1597–1611.