

The Perspectives of Families and Services
in
Early Psychosis

Christine J. Day

Supervised By:

Prof. Elizabeth Perkins

Prof. William Sellwood

Dr Helen Lockett

22nd of June 2015

Submitted in partial fulfilment of the Doctorate in Clinical Psychology

Acknowledgements

I would like to thank my supervisors for their encouragement and support, I feel privileged to have had the opportunity to work with them and value everything I have learnt from them during this process. I would especially like to extend my gratitude and thanks to the fifteen case managers for the time they gave up to participate in my research. Finally I would like to thank my husband and daughter for their patience, understanding and unshakable ability to make sure fun has stayed on the agenda throughout the challenges we have faced over the last three years.

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Introduction: Thesis Overview

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area of study and o...
Psychosis is a term... core symptoms that are...
considered psychotic include delusions and hallucinations (Division of Clinical...
Psychology [DCP], 2014; National Institute for Health and Care Excellence [NICE],...
2014). Hallucinations are perceptual experiences in the absence of any real stimulus and...
can be experienced via any sensory modality. Psychosis is commonly associated with...
auditory hallucinations, such as hearing voices or sounds (DCP, 2014; Garety, Kuipers,...
Fowler, Freeman & Bebbington, 2001; NICE, 2014). Delusions are ideas and beliefs that...
are distinctly unusual or bizarre. People experiencing psychosis commonly report...
persecutory delusions (being monitored or plotted against) and grandiose delusions (having...

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Introduction: Thesis Overview

This thesis contains two chapters, the first is a literature review and the second an empirical paper. This introductory section aims to provide a background context for the area of study and outline the key elements of the thesis.

Psychosis is a term used to describe core symptoms that are considered psychotic and include delusions and hallucinations (Division of Clinical Psychology [DCP], 2014; National Institute for Health and Care Excellence [NICE], 2014). Hallucinations are perceptual experiences in the absence of any real stimulus and can be experienced via any sensory modality. Psychosis is commonly associated with auditory hallucinations, such as hearing voices or sounds (DCP, 2014; Garety, Kuipers, Fowler, Freeman & Bebbington, 2001; NICE, 2014). Delusions are ideas and beliefs that are distinctly unusual or bizarre. People experiencing psychosis commonly report persecutory delusions (being monitored or plotted against) and grandiose delusions (having special abilities or a connection with a famous person or idol). Core symptoms often impact on a person's behaviour, social interactions and relationships (Boydell et al., 2014; Boydell, Stasiulis, Volpe, Gladstone, 2010; DCP, 2014; Garety et al., 2001; NICE, 2014).

Difficulties associated with core symptoms can include social withdrawal, depression, anxiety, self-harm and suicide (DCP, 2014; NICE, 2014). Psychosis accounts for up to 37% of suicides across mental health conditions, with a higher prevalence of suicide within the first five years of onset (Addington, Williams, Young & Addington, 2004; Westermeyer, Harrow & Marengo, 1991; WHO, 2001). Active psychosis has been identified as the third most disabling condition when compared to both physical and mental health conditions across 14 countries (WHO, 2001).

Between 60% and 70% of people experience the onset of psychosis while still living at home with their families and still more report being in close contact with family members

(Addington, Coldham, Jones, Ko & Addington, 2003; Addington & Burnett 2004; Sin, Moone, Harris, Scully & Wellman, 2012). The family environment correlates with well-being and people are seen to recover earlier when they are engaged in positive relationships and supportive family dynamics (Boydell et al., 2010; Boydell et al., 2014; Erickson, Beiser, Iacono, Flemming, Lin, 1989; Kuipers, Onwumere, & Bebbington, 2010; McFarlane & Cook, 2007; O'Brien et al., 2006).

Family members report high levels of psychological distress following the onset of a relatives experience of psychosis (Addington et al., 2003; Boydell et al., 2014; Jansen, Gleeson & Cotton, 2015) and often play a significant role in caring for and supporting them (Sin, Moone & Wellman, 2005). Families' inclusion in service led care for their relatives is increasingly recognised as fundamental, often described in existing guidance and policies (NICE, 2014). For family inclusion and intervention to be relevant to families' needs, it is important to understand family members' experiences of their relatives' development of psychosis and their experience of mental health services. In addition, implementing psychological interventions with family members leads to improved outcomes (Bird et al., 2010). Therefore it is vital to understand how decisions to include families and offer family interventions are made. This thesis seeks to inform the reader of what is currently known about family members' experiences of psychosis and mental health services. In addition it seeks to explore how case managers working within an early intervention service make decisions about offering family interventions for people accessing their service.

Structure of Thesis

The thesis is divided into two chapters. The first chapter is a literature review centred on family members' experiences of a relatives' development of psychosis and contact with mental health services. The literature underlining the role of family members' in the

relation to community care and recovery is explored. This is followed by the description of the meta-ethnographic method implemented to identify and synthesise data from 23 qualitative papers. The analysis resulted in five themes (1) Systemic identity: understanding everything that existed before; (2) Maintaining the family's status quo in the face of change (3) System overwhelmed by crisis (4) Navigating a labyrinth of help and support: searching for answers (5) Three degrees of separation vs. three degrees of influence: working together or working apart. In the final phase of the synthesis, family members' experience is translated into a model expressing service needs from family members' perspectives. The review indicates that despite advances in knowledge and practice family member inclusion remains problematic in mental health services for first episode psychosis. This is clearly impacted upon by the response of frontline mental health staff to family members. This links the literature review to the empirical paper which looked at case managers' appraisals and implementation of family interventions in an early intervention service for psychosis.

It is widely recognised that the implementation of evidence based psychological interventions for psychosis is poor (Haddock et al., 2014; Kuipers, 2011) and the findings in the first Chapter indicated that frontline mental health staff can affect how families experience and engage with mental health services. Therefore the second chapter presents an empirical paper that centres on case managers' perspectives. The aim of the empirical paper is to explore decision making about the implementation of behavioural family therapy (BFT). In-depth interviews were conducted with 15 case managers working in an early intervention for psychosis service. Template analysis was used to identify core themes regarding the implementation of an evidence based family intervention (BFT). The findings are looked at from three different perspectives based on case managers' training (trained in BFT, not trained in any family intervention approaches) or their opinion of BFT (objected to use of BFT due to feeling sufficiently skilled in family work and/or being are

trained in an alternative approach to family intervention). The results indicated that organisational support is vital for the implementation of BFT. Case managers' beliefs about family inclusion also impacted on the way in which they included families in day to day activities. Decision making about BFT relied upon case managers' beliefs about whether families benefited from BFT, their confidence in selling or using BFT in practice and capacity to implement BFT alongside case management responsibilities. The empirical paper highlights the variability in case managers' practice and complexity of case managers' decision making about BFT. This could be simplified by a clear organisational message that prioritises family intervention, the use of objective assessments of family members' needs as well as recording family work and routine assessment of family interventions used.

Both chapters highlight barriers to family inclusion and the implementation of family interventions for early psychosis. Service users, family members and case managers are diverse groups. Therefore clear boundaries and pathways of care are necessary and require prioritisation from an organisational level. This could enable all families to receive consistent care opportunities and choice that is then translated into individualised intervention to address their needs.

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CHAPTER 1

Family members' experience of first episode psychosis and mental health services: a meta-synthesis¹

¹ Prepared for submission to Clinical Psychology Review (Appendix1)

Abstract

Aim: Family members often play an important caring role when a relative develops psychosis. Their informal care is beneficial to mental health service provision and the well-being of service users. Complex and multifaceted mental health difficulties can change family lives and become burdensome. This review aims to understand family members' experiences of first-episode psychosis and mental health services in an attempt to determine what family members need from those services.

Method: A meta-ethnographic approach was used to systematically review 23 published qualitative research papers. A quality assessment of the papers indicated that they were of a moderate to high quality.

Results: Five themes were revealed through meta-synthesis: (1) Systemic identity: understanding everything that existed before; (2) Maintaining the family's status quo in the face of change (3) System overwhelmed by crisis (4) Navigating a labyrinth of help and support: searching for answers (5) Three degrees of separation vs. three degrees of influence: working together or working apart.

Conclusion: A model of services based on need is presented. Better links between mental health services, primary care and communities could reduce the negative impact of onset and help-seeking. Family members would benefit from greater inclusion, communication and support from mental health services

Keywords: First episode psychosis, Family members experience, Qualitative, Meta ethnography, Mental health services, family inclusion.

Introduction

A reliance on family members to fulfil complex caring roles for relatives experiencing mental health difficulties has spurred services to provide community support since the late 1950's with growing demand following de-institutionalisation and a move towards community care in the 1960's (Brooker & Butterworth, 1991; Reed, 2008). The current understanding of family members' experiences of psychosis and services are predominantly understood under the umbrella term of, carer or caregiver (Eassom, Giacco, Dirik & Priebe, 2015). Principally a sole family member is identified as a "carer", neglecting the impact psychosis can have on all family members and risking the exclusion of family members who do not identify with this label (Guberman et al., 2003; Sin, Moone & Harris, 2008). A carer is defined by the Department of Health (DoH, 2008) as someone who:

"spends a significant proportion of their life providing unpaid support to family or potentially friends. This could be caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems." (p. 23)

The additional support alluded to in this definition includes a wide range of activities supporting relative's functional, financial, psychological and social needs (Sin, Moone & Wellman, 2005). The inadequacy and variability of current definitions of a carer is acknowledged as a poor representation of a heterogeneous group of people (DoH, 2008). Despite this, the label is maintained in current literature and clinical guidelines (The National Institute for Health and Care Excellence [NICE], 2014).

It has been estimated that in the UK £119 billion is saved by family members taking on a caring role (Royal College of General Practitioners, 2014) of which £1.24 billion per year is attributed to carers supporting family members with a diagnosis of schizophrenia (The Schizophrenia Commission, 2012). However, financial losses derived from opportunity

cost assessment are often overlooked and could produce a different economic picture (Van den Berg, 2006). Family members' inclusion is considered important in a relative's care because their response to their relative's behaviour is associated with the course and prognosis of psychosis (Koutra, Vgontzas, Lionis & Triliva, 2014). Research focused on *expressed emotion* highlights the relevance of families' emotional environment in early psychosis and the role of family members' beliefs in mediating that environment (Barrowclough & Hooley, 2003; Domínguez-Martínez, Medina-Pradas, Kwapił & Barrantes-Vidal, 2014; Leff & Vaughn, 1985; Lobban, Barrowclough & Jones, 2005; Rapsey, Burbach & Reibstein, 2015). Specifically, criticism, hostility and “*emotional over-involvement*” within a caring relationship have been highlighted as predictors of relapse (Brown & Birtwistle, 1998; Hooley, 2007; Koutra et al., 2014; Kuipers, Onwumere & Bebbington, 2010). In conjunction with this, service users recover earlier following a first-episode of psychosis when engaged in positive relationships and supportive family dynamics (Kuipers et al., 2010; McFarlane & Cook, 2007; O'Brien et al., 2006). In addition, there is evidence suggests a clear association between constructive social relationships, family relationships and service user well-being (Boydell, Stasiulis, Volpe & Gladstone, 2010; Boydell et al., 2014; Erickson, Beiser, Iacono, Fleming & Lin, 1989). Relationships clearly impact on service users' wellbeing and family members are consistently identified as key relational influences in recovery, thus the inclusion of family members in care and service delivery should be a foregone conclusion (NICE, 2014). Behaviours associated with *expressed emotion* are to be expected in any family and it is unfortunate that in the circumstances of many mental health problems what is considered a normal family response seems to have a toxic effect. Due to the role of *expressed emotion*, interventions such as behavioural family therapy ([BFT], Fadden, 2006) have been developed to focus on education, communication and problem solving skills, with a view to overcoming challenges posed by “*hostility*” and “*emotional over-involvement*”.

The impact of first-episode psychosis has on family members' wellbeing is widely accepted in terms of quality of life and burden (NICE, 2014; World Health Organisation [WHO], 2001). Providing regular care for a relative leads to experiences of psychological distress and burden in relation to their caring role (Boydell et al., 2014). Family members' beliefs are predictors of distress and beliefs that psychosis is long term with severe outcomes for themselves and their relative can predict negative appraisals of care-giving and heightened psychological distress (Koutra et al., 2014). In contrast, family members beliefs that symptoms are controllable, is associated with increased positive care-giving appraisals and reduced distress (Koutra et al., 2014; Onwumere et al., 2008).

Family members' reactions vary greatly, with some experiencing high levels of burden in contrast to others reporting low levels or no burden across outcomes (Koutra et al, 2014). However longitudinal research with larger community samples indicate that family members' experience of burden and distress are high with extreme periods of distress experienced following the onset of psychosis (Addington, Coldman, Jones, Ko & Addington, 2003; Boydell et al., 2014; Koutra et al., 2014).

It is such findings that have led to recommendations that mental health services provide clear information and interventions tailored for individual families alongside earlier and recurrent carer assessments (Addington et al., 2003; Boydell et al., 2010; Boydell et al., 2014; Koutra et al., 2014; Kuipers et al., 2010; Onwumere et al., 2008).

Specialist community based mental health services for first-episode psychosis have been developed to reduce relapse, support recovery and ensure the support of family members caring for a relative experiencing psychosis (WHO, 2001). This is reflected in international policies and guidelines which are explicitly inclusive of family members (DoH, 2008; International Early Psychosis Association Writing Group [IEPA], 2005; DoH, 1999; WHO, 2001, 2013). Unfortunately recommendations are not always translated into practice

and there appears to be minimal evaluation of family members' experiences of specialist services (Kuipers, 2011; National Schizophrenia Audit [NAS], 2012, 2014).

Surveys have endeavoured to understand family members' experience through the proxy of 'satisfaction' (NAS, 2012). Feedback concerning satisfaction with services for first-episode psychosis resulted in low response rates with inconsistent levels of satisfaction across services (NAS, 2012). A marginal majority of family members reported overall satisfaction. Family members who indicated dissatisfaction attributed this to not receiving clear information about their relatives' prognosis, exclusion from the care decision making process and barriers to accessing care and support to meet their own needs (NAS, 2014).

These areas of dissatisfaction are in direct contrast with the policies underpinning the framework for specialist mental health services for first-episode psychosis. However it is difficult to generalise or ascertain details about what family members actually experienced from the data reported (NAS, 2012; NICE, 2014; WHO, 2013).

It seems important to have a clearer understanding family members' experience of first-episode psychosis and mental health services, understand their needs and whether they are met by existing guidelines and practice (NICE, 2014). Previous reviews of qualitative research have included but not focused upon family members' experience (Boydell et al., 2010) and a recent review whose publication coincided with this synthesis focused on family members' experiences of help-seeking (Cairns, Reid & Murray, 2015).

In contrast the aim of this review is to form a broader understanding of family members' experiences of first-episode psychosis and mental health services. This is explored using a meta-ethnographic approach (Noblit & Hare, 1998). This review aims to understand family members' experiences from first noticing changes in a relative's presentation to supporting a relative living with first-episode psychosis in conjunction with support from mental health services. Family members' experiences are discussed and translated into an model of how mental health services might best support family members.

Method

Meta-ethnographic synthesis adheres to seven phases (Noblit and Hare, 1998): (1) Getting started, (2) Deciding what is relevant, (3) Repeated reading, (4) Examining the relationship between studies, (5) Translating studies into one another, (6) Synthesising the translation, (7) Expressing the synthesis of translation. These phases are described throughout the method, data analysis and results.

Phase one took place over a period of six months and involved a process of discussion, supervision and reading in order to develop ideas into a rationale and focus leading to the question posed and aims described.

Phase two involved the identification of relevant qualitative peer reviewed published papers for inclusion, carried out through systematic literature searches using six electronic databases; MEDLINE, PsycINFO, Science Citation Index, Science Direct, Scopus and Social Science Citation Index. Initial searches of [psychosis OR schizophrenia] AND [family OR carer] were carried out on each database listed. These searches were then cross referenced with further searches of [psychosis OR schizophrenia OR first episode psychosis OR first episode schizophrenia] AND [family OR family member OR relative OR carer OR caregiver OR parent OR mother OR father OR sibling] AND [Qualitative OR experience OR burden OR help seeking OR duration of untreated psychosis OR Distress OR Coping OR Stigma OR Mental Health Services OR Early Intervention Services OR mental health nurse OR psychiatrist OR support worker OR Care coordinator OR psychologist OR social worker] were also performed.

Search results were reviewed for papers meeting the following inclusion criteria: qualitative research documenting family experiences of first-episode of psychosis and family experiences of service provision or treatment as usual from primary and specialist mental health services. Articles were excluded if they were quantitative, reviewed existing

research, did not include family perspectives in relation to first-episode psychosis, if service users' had a diagnosis other than psychosis or schizophrenia or it assessed new or novel interventions not yet established as routine practice. From the 680 distinct peer reviewed papers identified 17 articles met inclusion criteria and a further six were identified from references listed by these articles. Resulting in 23 peer reviewed papers qualifying for review (Figure 1).

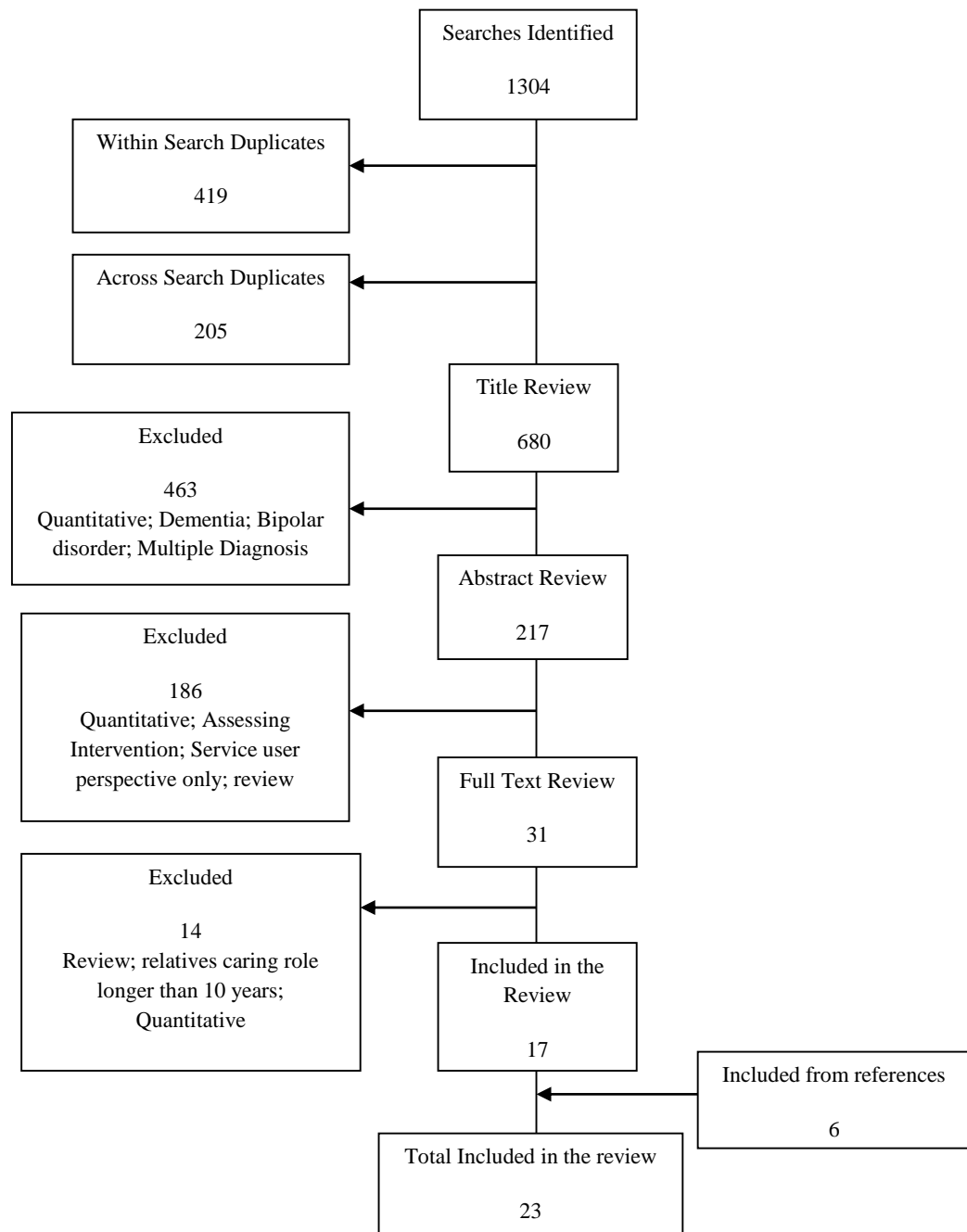


Figure 1. PRISMA Diagram of the Literature Search Process.

The articles were ordered chronologically and read in sequence of publication (earliest to most recent). Where publications occurred in the same year, chronology was maintained through the month of publication (Appendix 2). This order was maintained throughout the repeated reading process and during Phase four.

Research Characteristics

All 23 studies analysed family member accounts of acting in a caring role for a relative experiencing first-episode psychosis (Table 1). Five papers focused on help-seeking (Bergner et al., 2008; Connor et al., 2014; Czuchta & McCay, 2001; Monterio, dos Santos & Martin, 2006; Tanskanen et al., 2011; Wong, 2007). Whilst other papers centred on the experience of caring (Barker, Lavander & Morant, 2001; McCann, Lubman & Clark, 2011a; Tuck, du Mont, Evans & Shupe, 1997) and experience of mental health services including interactions with clinicians (McCann, Lubman & Clark, 2011c; McCann, Lubman & Clark, 2011d; Nordby, Kjønsberg & Hummelvoll, 2010; Penny, 2009; Sin, Moone & Harris, 2008; Sin, Moone, Harris, Scully & Wellman, 2012). A number of papers looked at the experience of stigma from a family member's perspective (Franz et al., 2010; McCann, Lubman & Clark, 2011b; Schulze & Angermeyer, 2008) and three papers focused on help-seeking and carers' experiences of mental health services during and following the help-seeking process (Cadario et al., 2011; Corcoran et al., 2007; Gerson et al., 2009). While the majority of papers' family member participants were parents (Table 2) other family members participated and two papers focused on siblings' experiences (Sin et al., 2008; Sin et al., 2012). Regrettably some papers did not state family member's roles (Czuchta & McCay, 2001; Schulze & Angermeyer, 2008).

While two papers explored the experiences of African American parents (Franz et al., 2010; Bergner et al., 2008) and another focused on British Pakistani families experience (Penny, 2009). The majority of the research did not clearly attach ethnicity to a specific

family member despite samples being described as diverse and including different ethnic groups (Figure 2). Research was conducted in both urban and rural areas of the UK, Australia, Brazil, Canada, Germany, Hong Kong, New Zealand, Norway and the United States.

The majority of family members were interviewed within the first 3 years of their relatives' contact with specialist mental health services (Cadario et al., 2011; Connor et al., 2014; Corcoran et al., 2007; Czutchta & McCay, 2001; Gerson et al., 2009; McCann et al., 2011a, 2011b, 2011c, 2011d; Monterio et al., 2006; Nordby et al., 2010; Penny, 2009; Sin et al., 2005; Sin et al., 2008; Sin et al., 2012; Tanskanen et al., 2012; Wong, 2007). Two studies interviewed family members within the first few months of their relative's initial contact with services (Bergner et al., 2008; Franz et al., 2010). Whilst other studies did not clearly define the duration of contact with services or in some cases single participants were estimated to have had contact with services for up to 10 years (Barker et al., 2001; Schultze & Anermeyer, 2008; Tuck et al., 1997; Wainwright et al., 2015). This becomes problematic in interpreting family members' experience of first-episode psychosis as existing literature has highlighted differences between family members' early and long-term experiences in relation to the process of adjustment to change (Addington et al., 2003; Boydell et al., 2014; Koutra et al., 2014; Onwumere et al., 2008;).

In many cases it was difficult to verify the number of families represented by participants. However of the 312 family members participating across 23 studies, 249 families were represented by at least one family member, with family membership remaining unclear for 32 participants (Figure 2). It would have been useful to understand differences and similarities of family members' experience within and across families. However studies are focused upon the care-giving role and in most cases a single family member is identified as a carer, despite a narrative across all studies that psychosis impacts on all family members.

Some participants were not exclusive to single papers and McCann et al. (2011a, 2011b, 2011c, 2011d) published four papers using data from the same 20 participants. This also occurred in papers authored by Bergener et al. (2008) and Franz et al. (2010) as well as Gerson et al. (2009) and Corcoran et al. (2007). However all 8 studies maintained a divergent research focus which warranted their inclusion. Of the studies included twenty-one used interviews to collect data while two used focus groups.

The 23 papers selected for this review used a number of qualitative methodologies and cited different aims. It was therefore unclear if the 23 papers could be synthesised collectively or had to be treated as distinct groups. Familiarity with the papers through the re-reading process highlighted that in spite of the different approaches and aims of each paper, they were all concerned with the broader theme of family members' experiences of psychosis (Barnet-Page & Thomas, 2009). Similarities between papers were established and it became clear that with no refutations across papers 'reciprocal translational analysis' (Noblit & Hare, 1998) could be used to draw out metaphors and shared experiences from the data alongside a 'lines-of-argument' approach (Noblit & Hare, 1998) to create a picture of family members' 'whole' experience from the parts of experience represented by the individual papers and their approaches.

Table 1.***Summary of Qualitative Papers Included in the Meta-Synthesis***

Citation and Country	Objectives	Method and Participants	Qualitative Approach	Study Results
Barker et al. 2001 UK	To explore narratives about developing schizophrenia	Semi-structured Interviews Service users (N=8) Relatives (N=8)	Grounded Theory	Four stage model of narratives: i. Events Preceding first episode psychosis (FEP), ii. FEP, iii. First hospital admission, iv. Current experience
Bergner et al. 2008 USA	To explore common themes pertaining to duration of untreated psychosis (DUP)	Interviews Included ten African American families of FEP service users (N=12)	Qualitative analysis	Four themes: i. Misattribution of symptoms/problem behaviours, ii. Positive symptoms as catalyst to seek treatment, iii. Views about adult patients personal autonomy, iv. System level factors (health care affordability and inefficiency)
Cadario et al. 2011 New Zealand	To examine the experience of FEP and access to treatment from a young person and carers perspective	Interviews 12 carers and service users dyads (N=24)	General inductive approach	Five themes: i. Lack of awareness of mental health, ii. difficulties as a barrier to accessing effective treatment , iii. Young people relied on others to seek help, iv. Emotional impact on carer pronounced, v. Mix of negative and positive experiences of services
Connor et al. 2014 UK	To understand delays in help-seeking that extend DUP	Semi-structured interviews 14 Family Dyads: Service user (N=14) Primary caregiver (N=14)	Framework Analysis	Five themes: i. Withdrawal, ii. Normalisation, iii. Stigma, iv. Fear, v. Guilt
Corcoran et al. 2007 USA	To examine family members view of patient symptoms and their impact on coping and help-seeking	Open-ended interviews Family members of 13 recent onset FEP (N=13)	Phenomenological data analysis	Themes i. Pre-morbid period: normal but vulnerable, ii. Mood symptoms and withdrawal, iii. Family struggles to understand and cope with change, iv. Breaking point – help seeking, v. What was helpful/Problem focus, vi. Future expectations: diminished/guarded hope
Czuchta et al. 2001 Canada	To understand parents experience of FEP	Interviews Subset of parents (N=5)	Thematic analysis	Three themes: i. Evolving change: what does it mean?, ii. Continuous help-seeking, iii. Experience of help-seeking: impact on parents
Franz et al 2010 USA	To explore effects of stigma on DUP	In-depth Interviews African American Family members (N=12)	Grounded Theory	Four Themes: i. Societies belief about mental illness, ii. Families' belief about mental illness, iii. Fear of the label of mental illness, iv. Raised threshold for initiation of treatment

Table 1**Continued**

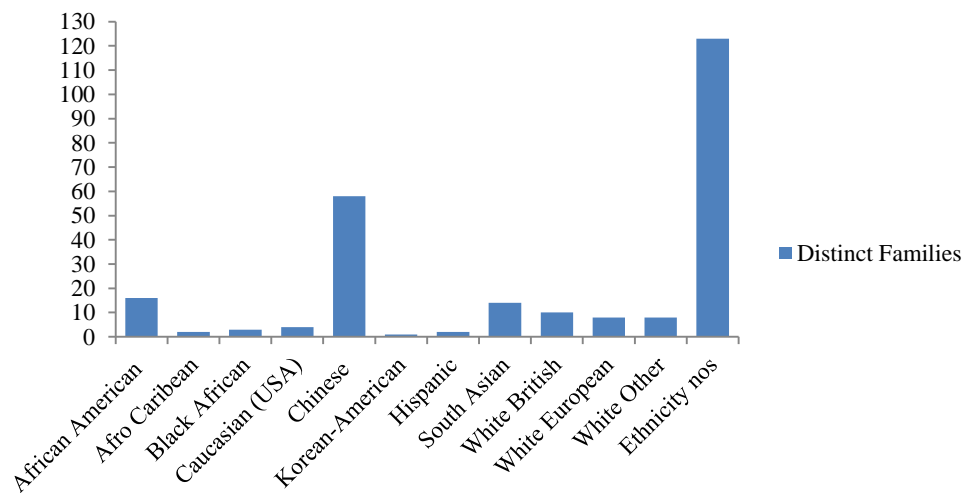
Citation and Country	Objectives	Method and Participants	Qualitative Approach	Study Results
Gerson et al. 2009 USA	To understand experiences of families seeking treatment for young people experiencing FEP	Open ended interviews 1 family member of 12 FEP patients and 2 family members of 1 FEP patient (N=14)	Phenomenological analysis	Five themes (data is unclear) i. Frustration with mental health system, ii. Diagnosis and involuntary hospitalisation, iii. Stigma and anger at staff, iv. Frustration following discharge, v. Wanting information vs gratitude for information
McCann et al. 2011a Australia	To understand the experience of first time primary caregivers of young people with FEP	Interviews first-time carers (N=20)	IPA	Six themes: i. Burdensome responsibility, ii. Rollercoaster and unpredictable experience, iii. Feeling responsible for their illness, iv. Coming to terms with change, v. Coming closer, vi. Maintaining hope
McCann et al. 2011b Australia	To explore how carers cope with stigma and maintain care giving.	Interviews Caregivers (N=20)	IPA	Three Themes: i. Being Open, ii. Being Secretive, iii. Reducing stigma related burden
McCann et al. 2011c Australia	To understand the experience of primary caregivers accessing FEP services	Semi –structured Interview Primary caregivers (N=20)	IPA	Three themes: i. GP as resourceful/un-resourceful as means of access, ii. Barriers accessing FEP services, iii. Carers knowledge and experience enhancing access
McCann et al. 2011d Australia	To understand primary caregivers satisfaction with clinicians response to them	Semi-structured Interview Primary caregivers (N=20)	IPA	Two Themes: i. Clinicians being approachable & supportive ii. Feeling undervalued as a carer
Monteiro et al. 2006 Brazil	To understand delays of six month before seeking help is common	Interviews Brazilian Patients (N=9) and relatives (N=15)	Anthropological discourse categorisation	Four Themes: i. Stereotyped misconception of mental illness, ii. Models constructed to understand patients problem, iii. Fear of psychiatric treatment, iv. Bad experience with services
Nordby et al. 2010 Norway	To explore and describe conditions that facilitate relatives involvement in treatment and recovery	Focus Groups Parents (15) siblings (3) (N=18)	Content analysis	Five themes: i. Encounter, ii. Support and Counselling (for relative), iii. Sharing information, iv. Nurturing hope, v. Acknowledging relatives expertise

Table 1
Continued

Citation and Country	Objectives	Method and Participants	Qualitative Approach	Study Results
Penny et al. 2009 UK	To explore culturally specific experience of families beliefs about psychosis and its treatment	In-depth Interviews Six families of Pakistani origin caring for FEP service users (N=11)	IPA	Three themes: i. A story of loss, ii. A social problem, iii. Divergent points on the path to change
Sin et al. 2005 UK	To explore carers experience of caring for a young adult experiencing FEP	Semi-structured Interviews Carers of sons with FEP (N=11)	Responsive-reader analysis	Six themes: i. Living together, ii. Caring intensively and extensively, iii. Knowing and caring, iv. Search for normalising activities, v. Support in caring, vi. Adjusting to caring role
Sin et al. 2008 UK	To explore the needs of siblings of individuals experiencing FEP	Semi-structured interviews Siblings from nine families (N=10)	Responsive-reader analysis	Key findings grouped as: i. Emotional impact, ii. Relationships in the family, iii. sibling role and coping patterns, iv. No positive gains from negative experience
Sin et al. 2012 UK	To explore the needs of siblings of young adults experiencing FEP	Semi-Structured Interviews Siblings (N=31)	Responsive reader and framework analysis	Six Themes: i. Roles and Involvement, ii. Diverse emotional response, iii. Impacts on relationships, iv. Coping Strategies, v. Resilience, vi. Service needs.
Tanskanen et al. 2011 UK	To investigate experiences of FEP and help-seeking	Interviews Service users (21) and their Carer/relative (9) (N=30)	Thematic analysis	Four themes: i. Not attributing problems to psychosis, ii. Worry about Stigma, ii. Not knowing where to get help, iv. Unhelpful service response.
Tuck et al 1997 USA	To explore the phenomenon of caring for an adult child with schizophrenia	Interviews Primary family caregiver (N=9)	Phenomenological data analysis	Seven themes: i. Struggling to reframe events as normal, ii. Seeking help, iii. Transformation of child, iv. Changing levels of hope, v. Endless caring, vi. Gathering meaning, vii. Preserving the self
Wainwright et al. 2015 UK	To explore the experience of supporting a relative experiencing FEP	Four focus groups 4-5 carers per group (N=23)	Thematic analysis	Four themes: i. psychosis from the relatives perspective, ii. Relatives fight with the mental health system, iii. Is anybody listening? Does anyone understand?, iv. Relatives coping
Wong 2007 Hong Kong	To identify crucial people and triggers in FEP help-seeking pathways	In-depth Interviews Chinese caregivers (N=58)	Content analysis	Four themes: i. Family caregivers initiators of help-seeking, ii. Informal network members as helpers in help-seeking, iii. School social workers bridging informal and formal help, iv. Family member experiencing FEP as a barrier to help-seeking

Table 2

<i>Role of Family Member Participants Across the 23 Papers Reviewed</i>	
Role	N
Mother	83
Father	31
Parent nos	83
Sibling	60
Aunt	3
Uncle	1
Grandparent	4
Spouse	3
Mother-in-law	1
Sister-in-law	1
Family member nos	42
Total	312



*Missing data: thirty-two family member participants excluded in from the graph due to unclear family membership

*Other named groups not represented due to unclear demographics: New Zealand Maori and Cook Island Maori

Figure 2. Representation of Ethnicity Across Studies Grouped by Distinct Family Membership.

Quality appraisal

Research papers were appraised using the Critical Appraisal Skills Programme tool (CASP, 2014). The CASP is designed to assist judgements made about the validity, methodological quality, rigour and overall value of qualitative research. Despite ongoing debate about the value of using quality assessment tools for qualitative research (Dixon-Woods, Shaw, Agarwal & Smith, 2004) the CASP meets appraisal recommendations explored within this debate (Dixon-Woods et al., 2004; Hannes, 2011). CASP outcomes are a descriptive representation of observations made, no research was excluded on the basis of the CASP appraisal and the majority of studies demonstrated a moderate to high quality (Table 3).

Data Analysis

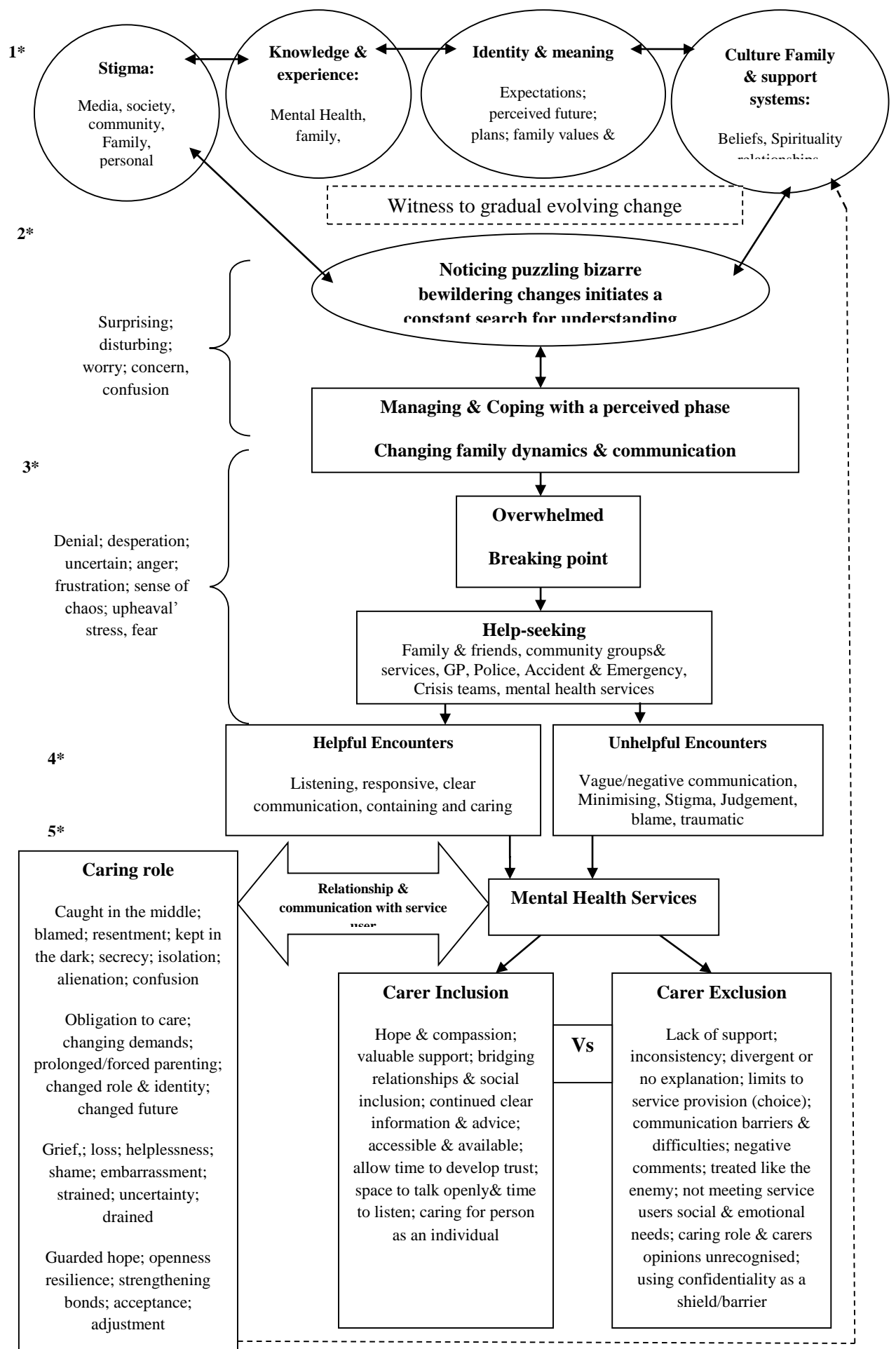
Phase four involved the extraction of metaphors and key concepts used by authors to describe family members' experiences of psychosis and mental health services (Noblit & Hare, 1998; France et al., 2014). Authors' descriptions and interpretations were represented in tables in preparation for phase five. This was achieved following the same chronology as phase three (Appendix 2). Extracted metaphors and key concepts were collated to form groups to develop emerging themes. Themes remained flexible and open to change until the process was complete for all 23 papers. The process was repeated a number of times to ensure common and contradictory experiences were not lost.

Phase five involved a process of juxtaposition that naturally developed into a model capturing the collective journeys of family members expressed throughout the papers reviewed (Figure 3).

Table 3
Results of Quality Appraisal Process Applied to the Publications Reviewed.

CASP quality assessment	Tuck et al. 1997	Barker et al. 2001	Czuchta et al. 2001	Schultze et al. 2001	Sin et al. 2005	Monteiro et al. 2006	Wong et al. 2007	Corcoran et al. 2007	Sin et al. 2008	Bergner et al. 2008	Gerson et al. 2009	Penny 2009	Nordby et al. 2010	Franz et al. 2010	Cadario et al. 2011	McCann et al. 2011a	McCann et al. 2011b	McCann et al. 2011c	McCann et al. 2011d	Tanskanen et al. 2011	Sin at al. 2012	Connor et al. 2014	Wainwright et al.2015
Was there a clear statement of the aims of the research?	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Is qualitative methodology appropriate?	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Research design appropriate to address the aims	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Recruitment strategy appropriate to the aims	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Data collected in a way that addressed the research issue	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓		✓
Researcher/participant relationship considered	x	x	x	✓	x	x	x	✓	x	x	✓	x	✓	x	x	x	x	x	✓	x	x	x	✓
Ethical issues considered	✓	✓	x	x	x	✓	✓	✓	x	x	✓	x	✓	x	x	x	x	✓	✓	x	✓	x	x
Data analysis sufficiently rigorous	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
A clear statement of findings	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
How valuable is the research?	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓

CASP, Critical Appraisal Skills Programme; ✓: journal article meets the criteria; x: Journal article does not meet the criteria



*Numbers 1, 2, 3, 4, 5: highlight areas corresponding with developed themes (Table 3)

Figure 3: Diagrammatic Representation of Phase 4 and 5: Relationships and Reciprocal Translation

Results

The narrative journey outlined by the model (Figure 3) was used to develop themes emerging from collective and conflicting meaning within and across authors accounts of the data. Analysis identified 16 subthemes (Table 4) that were refined into five major themes (Appendix 3).

Table 4

Phase Six: Themes Developed from Synthesis

1. Systemic identity: understanding everything that existed before

Identity
Knowledge
Culture
Society & Media

2. Maintaining the family's status quo in the face of change

Noticing changes
Acceptable explanations
Hidden fear

3. System overwhelmed by crisis

Breaking point
Struggling to cope

4. Navigating a labyrinth of help and support: searching for answers

Inconsistent professional contact and access
Answers & meaning
Emotional impact

5. Three degrees of separation vs. three degrees of influence: working together or working apart

What families/carers receive
What they want
The impact of caring

(1) Systemic Identity: everything that existed before.

The first theme captures the family as it existed prior to change and how these factors underpin their trajectory from noticing a relative's changing behaviour, to access and

continued support from mental health services. These factors include their identity, knowledge, culture, spirituality, wider society and the media.

Some family members describe relatives' normal and happy identities in conjunction with vulnerability and interpersonal difficulties preceding changes in behaviour (Barker et al., 2001; Corcoran et al., 2007; Penny, 2009). Across all papers the theme of loss, grief and adjustment begins to identify what may have been normal for family members as well as their expectations for their relative and themselves, prior to the onset of psychosis. They now described fears of delays in leaving home, prolonged parenting alongside diminished expectations for the future (marriage, academic achievement, independence) and changed relationships (Barker et al., 2001; Penny, 2009; Sin, et al., 2005).

Knowledge and awareness of mental health and psychosis seemed an important precursor to accessing professional support earlier. Wong (2007) identified that having the "correct perception", a less extreme and stereotyped concept of mental illness, facilitated the process of seeking help and confirmation. Knowledge seemed instrumental to family responses and a lack of awareness led to increased worry and fear (Tanskanen et al., 2011).

Culture was pivotal to family members' interpretation of symptoms, coping and help-seeking for specific ethnic groups (Cadario et al., 2011; Monterio et al., 2006; Penny, 2009). However, culture influenced all family members and understanding the continuum of cultural beliefs could lead to better engagement and communication (Cadario et al., 2011; McCann et al., 2011b; Penny, 2009; Tuck et al., 1997; Wong, 2007).

Spirituality also played a significant role for Brazilian and South Asian family members, who described a spiritual understanding of relatives changing behaviour and seeking guidance and support from spiritual leaders prior to seeking professional support (Monterio et al., 2006; Penny, 2009).

Stigma and media representations were considered barriers to the identification of a mental health difficulties due to the extreme stereotypes used (Barker et al., 2001; Cadario et al., 2011; Corcoran et al., 2007; Franz et al., 2010; Monterio et al., 2006; Schulze & Angermeyer, 2008; Wong, 2007). The portrayal of psychosis in wider society exacerbated fears and increased social withdrawal as a method of coping (McCann et al., 2011b).

Everything that existed before is the frame in which new experience is understood and responded to. This theme is intertwined with other aspects of family members' experience and could determine how support and mental health services are received.

(2) Maintaining the family's status quo in the face of change

This theme describes family members' search for a 'normal' explanation for changes in a relatives behaviour (Cairns et al., 2015). A broad range of symptoms are noticed by family members (Cadario et al., 2011; Connor et al., 2014) that can be vague and difficult to pinpoint and potentially influence delays in help seeking (Barker et al., 2001; Tanskanen et al., 2011). Many families describe the attribution of symptoms to adolescent behaviours (Barker et al., 2001; Bergner et al., 2008), Substance misuse (Tuck et al., 1997) and stress related to school and relationships (Corcoran et al., 2007; Monterio et al., 2006; Penny, 2009). In retrospect some family members describe a hidden intuition that something else is happening during this phase which is thwarted by a process of internal reasoning that minimised what they noticed (Corcoran et al., 2007; Tuck, 1997). Others realised the extent of the difficulties they witnessed looking back, causing feelings of guilt for potentially prolonging suffering (Cadairio et al., 2011; Tanskanen et al., 2011).

3. System overwhelmed by crisis

The third theme captures a breaking point in which family members initiate help-seeking. Family resources and coping strategies have been exhausted to no avail and the family system becomes overwhelmed by the exacerbation of presenting symptoms. Family

members describe managing extreme behaviours and disruption to family life becoming overwhelming (Crzucha & McCay, 2001; Corcoran et al., 2007). They are consumed by worry, confusion and become frustrated by difficulties communicating with their relative. Attempts to talk about their concerns are met with anger and denial (Barker et al., 2001; Corcoran et al., 2007; Penny, 2009; Sin et al., 2008). Families' existing coping strategies and resources are felt to have been ineffective leaving them with a sense of helplessness leading to a reassessment of meaning through philosophy, prayer and religion in a search for answers (Corcoran et al., 2007; Penny, 2009; Tuck et al., 1997). Family members may also try every approach available to them or start to push their loved one to socially re-engage (Corcoran et al., 2007). Seeking help from the wider family and friends, accessing community support and opening dialogues is helpful. Communication about their difficulties amongst family members and support networks is described as an important part of the help-seeking process and some family members seek professional support from health services at this stage. (Connor et al., 2014; Tuck et al., 1997; Wong, 2007). Other family members describe severe, often bizarre symptoms and dangerous incidents occurring which spurred them to seek professional help (Bergner et al., 2008; Cadairio et al., 2011; Tanskanen et al., 2011). This is a frightening and sometimes traumatic experience for family members eliciting a range of emotional responses within the family (Barker et al., 2001; Connor et al., 2014; Corcoran et al., 2007; Crzucha & McCay, 2001).

4. Navigating a labyrinth of help and support: searching for answers

The fourth theme describes family members' experience of seeking help and accessing support from professionals in the health care systems. Help may be sought from a general practitioner, emergency services, through inpatient admission or community mental health services, which may or not be specialist early intervention for psychosis teams. During this process family members want answers, a cure and meaning to be attached to their experience. However they are more frequently met with inconsistency and answers that

raise more questions. It can be an emotional and frustrating start to what can become an endless journey of care-giving (McCann et al., 2011a; Tuck et al, 1997).

Family members were often uncertain where to access help which led to approaching a number of health and mental health services prior to accessing the correct service. (Cadario et al., 2011). They found mental health services complex, fraught with obstructions and procedural shortcomings (McCann et al., 2011b; Wainwright et al., 2015). Denial of access was a problem due to limited resources and a need to persuade professionals that help was needed, requiring relatives to be seen as ‘convincingly unwell’ (Corcoran et al., 2007; Gerson et al., 2008; McCann et al., 2011b). Financial barriers are also experienced where insurance is required to access care (Bergner et al., 2008). Primary care services, including general practitioners, were often viewed as insufficiently equipped, lacking in knowledge that was helpful or supportive (Corcoran et al., 2007; Crzucha & McCay, 2001; McCann et al., 2011b; Wainwright et al., 2015)

Family members describe both positive and negative first encounters with professionals, from compassionate, respectful and helpful to ignoring, insensitive and evasive (Barker et al., 2001; Corcoran et al, 2007; Connor et al., 2014; McCann et al., 2011b, 2011c; Nordby et al., 2010). Communication difficulties with professionals caused frustration (Monterio et al., 2006; Tanskanen et al., 2011). In Hong Kong families found school social workers a valuable bridge between informal and formal networks, avoiding the labyrinth of service structure and procedures described elsewhere (Wong, 2007). Alongside frustrations, family members describe the necessity of intervention and admissions for their relative and had been relieved and grateful to receive help (Barker et al., 2001; Corcoran et al., 2007).

The questions and concerns family members have about their relative are met with the answer of a diagnosis or the term psychosis. Being told that their loved one has a diagnosis of schizophrenia, or more commonly in recent papers, is experiencing psychosis raises

more questions. Family members want to understand the meaning of these labels (Tuck et al., 1997) but find they are often left to their own conceptualisation (Barker et al., 2001). Psychosis can be experienced as an ambiguous, incoherent term capturing a broad cluster of experiences (Sin et al., 2005; Wainwright et al., 2015). Proactive efforts to carry out their own research, often results in a struggle to find accessible information, or synthesise conflicting accounts (Crzucha & McCay, 2001). Some families received insensitive, negative and damning accounts about the diagnosis from mental health staff (Gerson et al. 2008). Whilst other felt over optimistic accounts were unrealistic and unhelpful (Nordby et al., 2010; Penny, 2009).

The emotional impact of seeking help, receiving a diagnosis or explanation is broad and predominantly negative. Family members describe entering a process of grief and loss for their loved one, yet having a changed person in front of them who they are obliged to care for (Barker et al., 2001; Tuck et al., 1997). Family members feel shame, isolation, blamed, anger and loss alongside experiences of uncertainty, chaos and upheaval (Barker et al., 2001; Gerson et al., 2008; Tuck et al., 1997; Wainwright et al., 2015). Seeking professional help is an emotionally exhausting and frustrating process for most families.

5. Three degrees of separation vs. three degrees of influence: working together or working apart

The final theme covers family members' experiences of longer-term involvement with mental health services. It describes what family members receive from mental health services, what they express as an unmet need and their experience of taking on a caring role for a relative experiencing psychosis.

Family members describe relief to finally have their relatives' difficulties recognised (Crzucha & McCay, 2001). Mental health services are seen as acceptable, offering valued support and care for their relative as an individual (Barker et al., 2001; Wainwright et al., 2015). Participants talked about valuing a supportive environment where they are listened

to, can talk openly to staff and receive information about the service and their relative (McCann et al., 2011d; Nordby et al., 2010). There is however dissatisfaction and friction described across the papers indicating a tense relationship between family members and mental health services (Boydell et al., 2010). In direct contrast to the positives, some family members do not feel listened to or taken seriously (McCann et al., 2011d; Wainwright et al., 2015). Medication provided to manage symptoms is noted as helpful but also a major concern, particularly with respect to side effects (Barker et al., 2001; Cadario et al., 2011). Confidentiality is a source of contention between family members and services. It is often interpreted as a lazy method to avoid family involvement or a way to easily exclude them from care planning and clinical consultations (McCann et al., 2011d; Wainwright et al., 2015). Family members alluded to a lack of empathy from staff, experiencing judgment and stigmatisation even a sense of being perceived as the enemy (Franz et al., 2010; Wainwright et al., 2015). Information has to be sought out proactively and communication and inclusion is fragmented or absent in many family members' experiences (Cadario et al., 2011; Gerson et al., 2008; McCann et al., 2011d; Wainwright et al., 2015). Siblings' accounts indicate that they too are often overlooked by mental health services (Sin et al., 2012).

There is an overwhelming request for information across the studies; family members want to understand what psychosis is, how to support their relative and manage symptoms and crisis situations (Barker et al., 2001; Gerson et al., 2008; McCann et al., 2011c, 2011d; Wainwright et al., 2015). Siblings request specific coping and communication skills, to assist their supportive role in the family as well as support groups and a space to talk (Sin et al., 2008; Sin et al., 2012). Socially inclusive activities and supporting families to access activities seemed a priority for a number of family members (Penny, 2009; Sin et al., 2005). The majority of participants wanted to be valued and included in their relatives care, to be invited into discussions with staff and supported in their often fulltime caring role

(McCann et al., 2011d; Nordby et al., 2010; Sin et al., 2005). Family members acknowledged and understood that deficits in services as caused by limited funding for mental health meant they had to work within restrictive limitations (Schultze & Angermeyer, 2008). Despite this they were frustrated by limitations and lack of choice (Schultze & Angermeyer, 2008; Sin et al., 2005).

Family members' experiences were influenced by their relatives' well-being (Barker et al., 2001) and they fulfilled multiple practical and emotional roles at different times (Sin et al., 2005; Sin et al., 2008; Sin et al., 2012). Accepting the diagnosis led to a sense of relief which, in turn, facilitated adjustment to their situation (Sin et al., 2006). Where families had an exaggerated sense of hope, they experienced attrition leading to disappointment, until expectations shifted to more realistic goals (Penny, 2009; Nordby et al., 2010; Wainwright et al., 2015). Family members describe a journey fraught with frustration, stress, anger and outrage (Cadario et al., 2011; Gerson et al., 2008; McCann et al., 2011d; Penny, 2009; Wainwright et al., 2015). Being kept in the dark and excluded by services, exacerbated family members' struggle (Cadario et al., 2011; Gerson et al., 2008; McCann et al., 2011d). However inclusion by services supported families to develop stronger family relationships and resilience (Cadario et al., 2011; Gerson et al., 2008; Sin, et al., 2012).

Translating synthesis into expression

In phase seven the results of the synthesis are translated to effectively communicate the findings to different audiences. The findings of this synthesis have been represented in a model. From the five themes developed an indication of what family members needed from services throughout their journey became apparent. The model presented aims to communicate a family's needs regarding a family inclusive practice for first-episode psychosis (Figure 4).

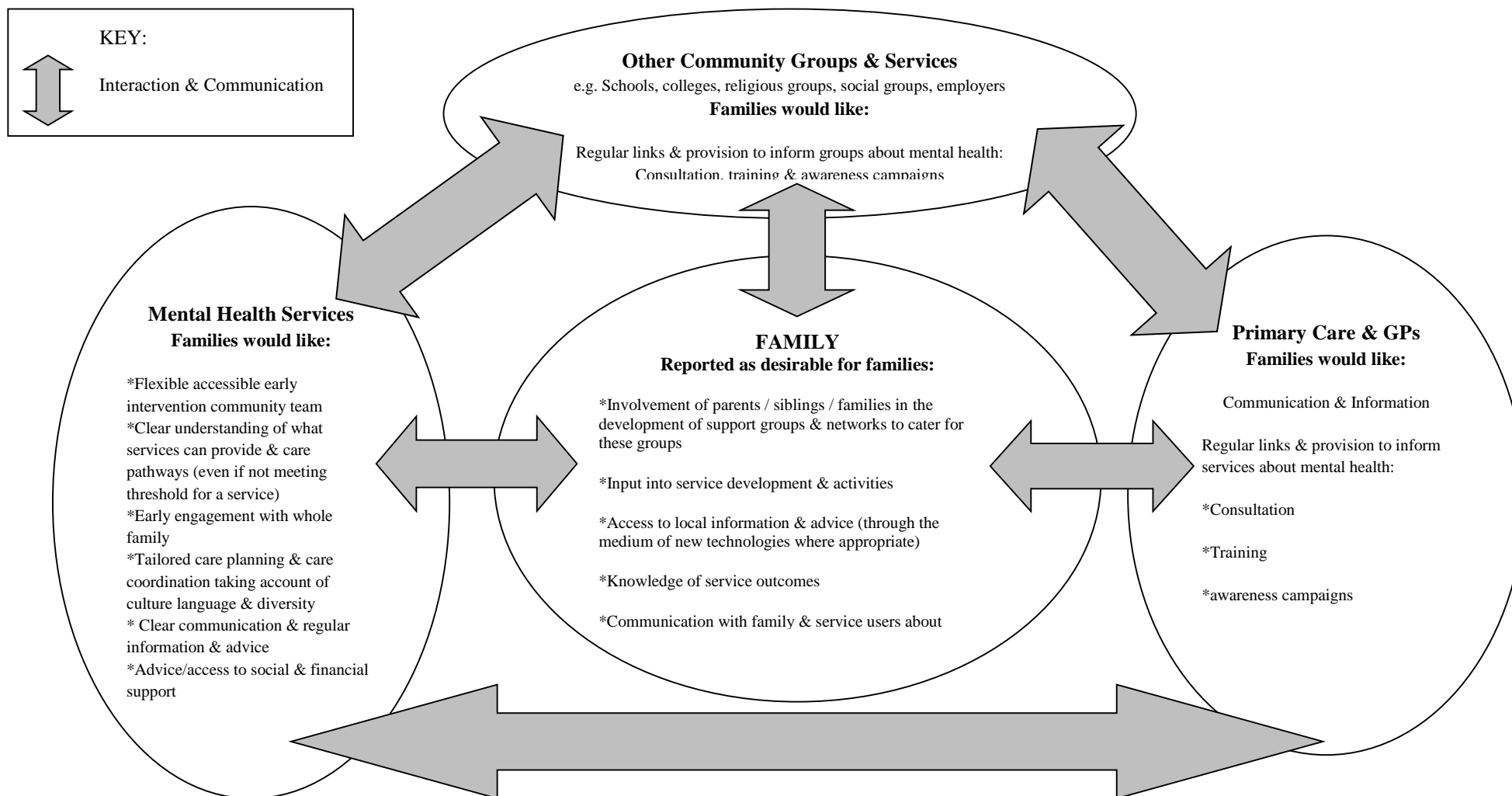


Figure 4. Phase 7: Expression of Service Need based on Family Experience

Discussion

The accounts of the 312 family members described in the papers reviewed reflect a disparity between policy and practice (NAS, 2014) which has been reported elsewhere (Haddock et al., 2014). This review highlights the exhausting emotional journey which family members go through before and during the process of seeking professional help.

Family members express experiences of grief and confusion when they first contact mental health services and how professionals communicate with them impacts on how they feel and cope. These findings support previous research indicating family members experience extreme periods of distress following the onset of psychosis (Addington et al., 2003; Boydell et al., 2014; Koutra et al., 2014). Family members seem to value any time and information that mental health services provide and the support they receive. Family inclusion does happen to a degree in the experience of these family members but it does not meet their needs. Findings also indicated that family members involved in their relatives care experience adjustment, re-evaluation of resilience and practiced coping, leading to a reduction in distress over time which is in line with previous research (Onwumere et al., 2008).

Given that family relationships are important factors in recovery and wellbeing (Boydell et al., 2014; Boydell et al., 2010; Erickson et al., 1989), it seems clear that family members' experiences are both important and necessary for consideration not just for their sake, but the best outcomes for the service users themselves.

Limitations

This meta-synthesis emphasises related features in family members' experiences of psychosis and its treatment across diverse groups and geographical areas. Despite differences in accessing professional care, family members describe a similar array of experiences, which is also consistent with previous reviews (Cairns et al., 2015). However

this review has a number of limitations. First, family members included in the majority of the papers reviewed were identified as primary carers or care-givers which excludes the perspective of other family members (Guberman et al., 2003). The papers underplay the impact of established family members' roles, providing unclear demographic information. The majority of participants were parents (Table 1) who when compared to siblings had different experiences and needs within the family and from services (Sin et al., 2012). This raises important questions about the use of an umbrella term like 'carer' as a criterion for inclusion in research and services. For example relatives experiencing First-episode psychosis clearly impact on siblings' well-being despite their role not being considered that of a carer (Sin et al., 2012).

Family members describe early observations of their relatives' changing behaviour. The behaviours described by family members may not have developed into psychosis or met the criteria for access to specialist mental health services, if help had been sought earlier. Early changes are subtle and similar to depression or anxiety and therefore may not have met the threshold for EIS. This challenges ideas that community interventions could reduce the duration of untreated psychosis, if the aim is to allow access to EIS. Funding and capacity to work with prodromal symptoms of psychosis and at risk groups would be required to meet this demand (Cairns et al., 2015; National Institute for Mental Health in England [NIMHE]. 2008). It also seems understandable that family members would attribute earlier symptoms to adolescence and it would be interesting to know if family members of relatives who do not go on to develop psychosis or access services have similar experiences.

This synthesis is clearly limited by the research it reviews and despite the use of a quality assessment tool (CASP, 2014) the effectiveness of appraisal methods for qualitative research remains an area of debate (Dixon-Woods et al., 2004; Hannes, 2011). The papers reviewed had individually small samples that may not represent alternative accounts held

by family members or those difficult to engage within the geographical area. However, families participating may not be representative and may have volunteered for the research because of particular difficulties they have with their relative or the service. It can be seen from Table 3 that overall the studies were of relatively good quality, although there was a consistent pattern of a lack of consideration of relevant ethical issues such as the researcher participant relationship. Further qualitative studies should address these issues.

The influence of immersing oneself in data by re-reading papers already framed within the views of the authors is also a limitation. Authors' language use was often reminiscent of mental health services and guidelines. This may have been a way of expressing findings for a mental health care professional readership or a professional interpretation bias. As the author of this review I too must acknowledge the influence of working in mental health care settings and how this may have influenced the way in which papers were interpreted and expressed.

Implications

The findings of this meta-synthesis have implications for service development and the audit of family involvement. It indicates common areas of need for family members taking on a caring role and highlights how these needs could be met by mental health services to improve engagement with families.

We now have an understanding of participating family members' experiences of psychosis and mental health services for first-episode psychosis. The synthesis of their experiences has underlined clear needs and suggested how they could be met by mental health services (Figure 5). The unmet needs identified by family members across the 23 papers reviewed could be addressed by a number of family interventions purposefully designed to meet the needs of families. This includes pragmatic family interventions such as Behavioural Family Therapy (Fadden, 2006) as well as cognitive behavioural approaches

(Barrowclough & Tarrier, 1997) systemic family therapy (Burbach & Stanbridge, 2006) and an open dialogue approach (Seikkula, et al., 2006). Provision of formal family interventions is a fundamental expectation for anyone experiencing psychosis (NICE, 2014).

Although what has been highlighted repeats indications from previous research and the current service frameworks (Department of Health, 2000) it summarises, unifies and consolidates previous work into a coherent story relating to family involvement in care. Despite advances in knowledge and practice why does family member involvement in mental health services for first-episode psychosis remain problematic? One barrier seems to be clear; the way that frontline mental health workers' deal with families continues to pose problems. But what are their views on working with families and what problems do they face in implementing good practice?

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CHAPTER 2

Case managers' decision making regarding the implementation of behavioural family therapy for psychosis: real world evidence based practice.²

² Prepared for submission to Journal of Occupational and Organisational Psychology (Appendix 5)

Abstract

It is widely recognised that implementation of evidence based psychological intervention for psychosis is poor. Case managers are vital to successful delivery of such interventions. The aim of this research was to explore case managers' decision making about the implementation of behavioural family therapy (BFT) for psychosis. Fifteen case managers working in an early intervention for psychosis service were interviewed. Interviews were analysed using template analysis which revealed five themes; (1) sabotaged by the system, (2) the big I in team, (3) searching for ecological validity, (4) erring on the side of caution, (5) repressed rebellion. A narrative of case managers' decision making is discussed from three perspectives: case managers trained in BFT, case managers who have not received family intervention training and case managers trained in alternative family interventions and/or object to using BFT. It is concluded that organisational support for family interventions is crucial to structured implementation of family interventions. Training tailored to case manager needs, comprehensive assessment of families' needs and use of outcome measures are recommended.

Practitioner points

- Contributes to current understandings of implementation of evidence based practice in a clinical practice
- BFT training increases the likelihood of family interventions.
- Subjective methods used to make decisions about offering BFT limited its implementation.
- Limited organisational support and capacity are considered the main barriers to the implementation from a case manager's perspective.

Introduction

Family interventions for psychosis have a long standing evidence base (Marshall & Rathbone, 2011) and are considered vital for individuals experiencing psychosis and their families. They lead to reduced relapse, improved engagement and adherence with medication (Armijo et al., 2013; Bird et al., 2010; Bustillo, Lauriello, Horan & Keith 2001; Pilling et al., 2002). Similarly, social and vocational functioning in addition to quality of life is seen to improve following engagement with these interventions (Garety et al., 2006; Hogarty, Anderson & Reiss, 1986; Leff, Sharpley, Chisholm, Bell & Gamble, 2001). Family members have indicated that family interventions can have a positive impact on experiences of psychological distress, family functioning and relationships (Campbell, 2004; Cuijpers, 1999).

The National Institute for Health and Care Excellence (NICE) guidance recommends that family intervention should be offered to all families of service users experiencing psychosis (NICE, 2014). NICE guidance also highlights the importance of monitoring and reviewing service user and carer satisfaction, access, inclusion and engagement in this context (NICE, 2014). The decision making processes around offering family interventions is also named as an important area of review. Despite these guidelines (NICE, 2014), their use in clinical practice remains limited, becoming a commonly discussed yet unresolved disparity between evidence base and practice (Bailey, Burbach & Lea, 2003; Berry & Haddock, 2008; Fadden, 2006; Brent & Giuliano, 2007; Haddock et al., 2014; Kuipers, 2011). In Early Intervention Services (EIS) only a small number of trained practitioners report using family interventions (Berry & Haddock, 2008; Becker, Nakamura, Young & Chorpita, 2009; Bird et al., 2010; Cohen et al., 2009; Eassom, Giacco, Dirik & Priebe, 2015; Haddock et al., 2014; Sin, Livingstone, Griffiths & Gamble, 2014) and a recent audit demonstrated that in community mental health teams less than 2% of eligible service users receive family intervention (Haddock et al., 2014).

The development of the Meriden Behavioural Family Therapy (BFT) approach presents community services with a framework to facilitate family therapy in practice (Fadden, 1997, 2006). The Meriden BFT package includes a five-day training course and a framework for clinicians to provide manualised, skill-based family therapy alongside, support and supervision (Burbach, Fadden & Smith, 2010; Fadden, 1997, 2006).

The implementation of BFT has clearly faced difficulties in practice and this has been investigated in detail by Gráinne Fadden (2006). Barriers included organisational failures to prioritise BFT; lack of support or reduced caseloads for clinicians; lack of maintenance of clinicians' skills through practice (which in turn impacts on their confidence to deliver BFT) and specific interactions between organisational structures, clinicians, family members and service users. Clinicians and organisations are often overwhelmed by high caseloads and changing demands within the system, leaving family work as something additional and not routinely recorded, measured or supervised (Fadden, 2006).

A review of 43 studies examining the implementation of family interventions found that top down support, promotion of family working amongst colleagues, collaboration and individuals' motivation and enthusiasm were driving factors (Eassom et al., 2015).

Effective delivery of family interventions also required clinicians to attain additional skills around collaborative working, and professional interpersonal qualities such as projecting a non-judgemental, non-blaming approach (Eassom et al., 2015).

Despite consensus that family inclusion and intervention are essential in EIS (Becker et al., 2009; Birchwood et al., 2013; Craig, 2003; Fadden et al., 2004; Kuipers, 2011, Marshall, Lockwood, Lewis & Fiander, 2004; Marshall & Rathbone, 2011), there are benefits for families (Campbell, 2004) and clear aspects of services and clinicians' qualities that enable the provision of family interventions (Eassom et al., 2015; Fadden et al., 2011; Sin et al., 2014) implementation rarely happens (Haddock et al., 2014). However, there is no research

that focuses on understanding what is currently happening at the frontline in EIS teams or that captures how case managers make decisions about offering family interventions to families accessing EIS. This is an important area to pursue, case managers are frontline staff often relied upon to introduce service users and their families to the service, inform them about psychological interventions and provide interventions as part of their role.

This study aims to explore the way in which case managers make decisions about offering and implementing family interventions in practice. This will be explored within an EIS currently implementing the Meriden BFT model. Given the lack of previous research in this area a qualitative approach has been adopted to enable an exploration of the types and range of factors which influence case managers' decision making in relation to BFT.

Aims:

To understand case managers' perspectives on BFT, including their development and maintenance.

To explore how case managers' perspectives influence decisions and practice in relation to referrals to and the implementation of BFT.

The Service³

The early intervention service covers a geographic area populated by 1.5 million people. Nine percent of the population is represented by ethnic minorities and over 17% of the population live in areas within the top percentile of the deprivation index. The service currently functions within a hub and spoke team model, splitting the service into three spokes central to specific areas (Figure, 1). The hub team consists of psychologists, administrators and management that feed into spoke teams. Overall there are

³ Information about the service was received from service materials and the service NHS Trust's media site and online conference materials, references are omitted to maintain a reasonable level of confidentiality.

approximately 780 service users distributed across the spokes, and 90 case managers of which 25 have been trained in BFT.

The service provides input for up to three years for young people aged 14-35 who are experiencing symptoms of psychosis or at risk of developing psychosis.

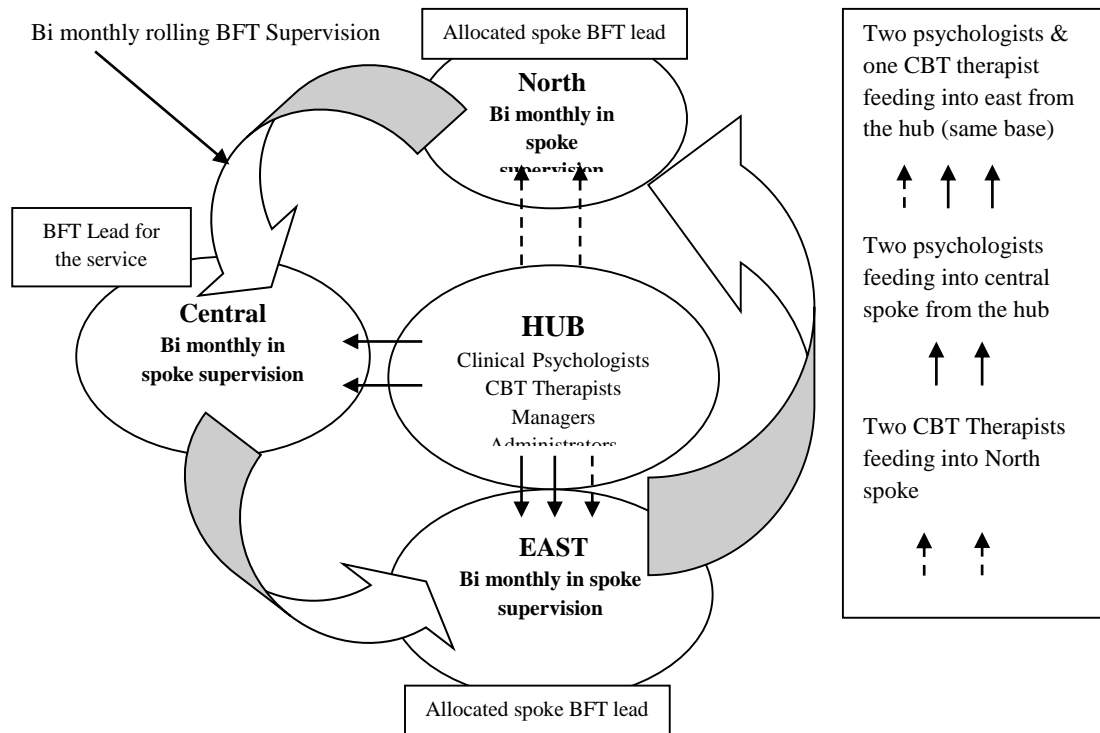


Figure 1. Model of Service and BFT support/supervision design

Method

Research Design

A qualitative approach was taken to explore case managers' decision making about offering BFT to families accessing EIS.

Sample

Fifteen qualified case managers (four assistant case managers) with caseloads of 12 to 22 service users were recruited to the study (Table 1). All had comparable experience, training

and levels of responsibility and so will all be referred to as case managers throughout this paper.

Recruitment

Following team managers' approval, all case managers were invited to participate and provided with information sheets (Appendix 5) by email and during team meetings.

Participants did not have to be trained in BFT or currently involved in any formal family work to participate. Interviews were conducted outside case managers' working hours in rooms booked within the EIS spokes or at participant's homes dependent on case managers' preference. All participants received a £10 gift voucher as compensation for their time.

BFT training had been attended by nine participants in 2011 (N=2), 2012 (N=6) and 2013 (N=1). Of these case managers, five started BFT with a family within two months of training and a total of six case managers trained in BFT have worked with families using a formal BFT approach. The remaining three report using BFT in an "ad hoc" way as part of their everyday practice (Table 1).

Research Approach

In-depth interviews were audio recorded and transcribed. Template analysis (King, 2004) was used to inform data collection. Template analysis, like many other qualitative approaches involves the development of thematic codes and their use to code text.

However the aims of this research could not be approached using methodologies such as Interpretive Phenomenological Analysis ([IPA], Spinelli, 2005) and grounded theory (Glaser & Strauss, 1967) because of the researcher's prior experience and the consideration of a priori themes. In addition, if for example, IPA had been used, the primary interest would be in the individual and analysing the individual accounts of the participants.

Analytical comparisons across the samples in IPA are secondary.

In conjunction with this the researcher can explore broader themes, using a bottom up approach influencing the interview process, templates and themes (King, 2004). It is a fluid process, in which both interviews and templates evolve alongside each other until a final template is developed, that captures the data (bottom up) in a way that also addresses the focus of the research (top down). Interviews and data analysis evolved from initially seeking a broad understanding of case managers' experience of family work, to focusing upon case managers' decision making about BFT.

Table 1.

<i>Demographic information⁴</i>		N
Male		5
Female		10
Average Age		39
		(Range 26-59)
Ethnicity		
White British		15
Professional Training		
Nurse		14
Social worker		1
Average caseload		
Full-time		19
		(Range 15-22)
Part-time		13
		(Range 12-15)
Average number of years working in EIS		6
		(Range 9months-11years)
Spoke Team		
North		2
Central		4
East		7
BFT Training		
Trained		9
Not Trained		6
Number of families received BFT		
Complete		13
Disengaged		4
Ongoing		1

⁴ Demographic information merged to protect anonymity of participants.

Ethical Review and approvals

The research received ethical approval and sponsorship from the University of Liverpool and further approvals from the relevant NHS Trust. Informed written consent was obtained prior to participation (Appendix 5). Additional verbal clarification that raw data would not be accessible to supervisors working within the service and would be suitably anonymised, was given to all participants.

Analysis

The following process of analysis was adopted;

- (1) A priori themes developed based on a loose structure forming the interview, e.g. case manager's role; experience of working with families; perception of BFT.
- (2) Listening back to interviews with corresponding transcripts to check the accuracy of the transcripts and develop familiarity.
- (3) Through supervision exploring interview themes in the first three interviews, developing an initial template from emerging themes, clustering themes and subthemes whilst noticing gaps in understanding and adapting the interviewer's approach.
- (4) Repeating the process in blocks of 3 allowing subsequent interviews and template to evolve.
- (5) With each evolution of the template reapplying the new template to preceding interview transcripts.
- (6) Listing corresponding transcript codes with themes to identify bias and adapting the template if bias was identified.
- (7) Reapplying the template to all transcripts and finalising the template (Appendix 6).
- (8) All stages of template development are retained to allow an audit of the analysis process

Researcher Characteristics

Due to the potential impact of researcher bias on qualitative analysis researcher characteristics are important to consider (Malterud, 2001). The researcher is a 37 year old white British woman and a final year trainee clinical psychologist. She was previously employed by the EIS service involved in this study, as a research assistant and a psychology assistant. During this time the researcher had contact with case managers and had attended BFT training, briefly using BFT prior to commencing clinical psychology training. The researcher is passionate about family interventions and values BFT as an approach, viewing it as a basic but effective intervention. To balance the researchers' perspective, an exploration of relevant literature was conducted prior to and alongside data collection. Supervision was provided from an experienced qualitative researcher who has no affiliations with EIS or family intervention work for psychosis.

Results

Five themes emerged from the data and are discussed (Table 2). Themes are numbered and broken down into subthemes alphabetically; the first two themes underpin any decisions made about BFT and are therefore the starting point of this analysis. (1) Sabotaged by the system, describes the context and values of the organisation in which case managers worked and made decisions about BFT. (2) The big I in team, captures the tension between the organisational landscape and case managers' as well as variation in case manager's views about general work with families. Case managers' decision making about BFT differed in relation to training. The decision making process leading to case managers' deciding whether to refer, offer and initiate BFT with families is related to training and described within the following three themes. (3) Searching for ecological validity, describes the perspectives of case managers' trained in BFT, and how they implemented BFT training in practice. (4) Erring on the side of caution, captures decision making about

BFT by case managers not trained in any family therapy approaches (hereafter referred to as untrained case managers). Untrained case managers have concerns about BFT and are cautious of the impact offering BFT would have on their engagement with families. The fifth theme (5) Oppressed rebellion, describes case managers trained in an alternative family intervention⁵ and /or objected to using BFT; they described being skilled in working with families and their views not being acknowledged. They also cited frustration with professional inequality within the service.

Table 2.

Five Themes that Emerged from the Data

1	Sabotaged by the system The organisation from a case managers perspective
2	The big I in team Case managers views and how they generally work with families
3	Searching for ecological validity Trained case managers making decisions about BFT alongside case management and changing demands
4	Erring on the side of caution Unsure about BFT, negative views and capacity prevents referrals
5	Oppressed rebellion Alternatively trained and/or objecting to BFT, deciding not to refer to BFT and using their own approaches to family interventions, skills are under valued

1. Sabotaged by the system

1a. “The system is set up to maybe not be as inclusive of carers as it could be” (P003, line 472)

Although the principles of family inclusion and family therapy are explicitly mentioned in the guidelines for EIS (NICE, 2014), case managers painted a different picture in practice. Organisations were reported to be target driven with funding dependent upon the attainment of these targets. While targets were recognised to be important, case managers

⁵ Undisclosed to protect the anonymity of this participant

talked about the tokenistic assessment of their work via targets resulting in tension between case managers and their employer.

All the AQuA targets and CQUIN stuff it's all about payment isn't it. ... The things that we're targeted on you ask all the case managers and they are probably going to say it's not really telling you anything about quality (P013, line 455)

They are not bothered whether it works or not they are just bothered about whether you have ticked the right box for your AQuA target because that's what you are going to get in trouble over ... you probably could just write anything in the daily and I don't think they'd even see it to be honest (P012, line 574)

You've got these targets to meet, you've got this job to do... 'it doesn't match it doesn't marry up' (P015, line 864)

2. The big I in team

2a "We've got core things that we all do but I think everyone's approach ... is different" (P001, line 252)

The current targets prioritise individual work with service users often sidestepping an organisational focus on family work. Use of BFT therefore comes down to the individual case manager's beliefs about its benefits. There were two different discourses about family inclusion, one group of case managers believe that family work is integral to their role:

I don't actually think that you can do this work without including the relatives or the families (P009, line 109)

I'd kind of encourage them from the beginning that it would be a good idea for family to be involved because probably the fact that they don't want to speak to their family about the problems is probably one of the problems in itself (P002, line 109)

Another group of case managers believed that the inclusion of family members is separate from or additional to working with service users. In addition, families may be seen as a barrier to what is perceived to be more beneficial ways of working:

I mean it depends what that individual service user wants, requires and is best for that service user (P008, line 55)

You probably spend more time talking to the family and the service user is getting frustrated because ... the family will be there interfering for want of a better word ... wanting you to do things their way ... it impacts on the length of time you can actually spend with the service user actually doing something (P010, line 71)

The interactions with families including the way in which confidentiality is approached when a service user has indicated they do not want family members informed about their care, is also distinctive. Those who view family members' inclusion as integral to their role report that service users rarely refuse the inclusion of other family members. When refusal does occur it is negotiated:

It's about reaching a shared understanding and viable way forward ... So it's a negotiation (P003, line 162)

I persuaded him ... to let his Mum come to one of the appointments ... she came to one of the sessions ... it was really, really positive and as a result of that their relationship is so much better now and he is so much better. (P004, line 490)

Case managers, who view family inclusion as secondary, report a pre-eminent responsibility to service users and talk about needing to be cautious when interacting with their families:

You [family member] can tell me anything you like but I can't tell you what's going on with a family member [service user] ... it's acknowledging their frustrations and also when they start venting quite loudly on occasion ... it's trying to manage that in a professional manner ... acknowledge what their concerns are and the difficulties that they face and trying to generalise the feedback to them. [All of] That without breaking confidentiality (P015, line 234)

They [family members] tend to hold it as gospel [fact], what you've said. So if you say the wrong thing ... it will be going for years you know 'you said this and it's not'. So you've just got to be so careful with what you say (P012, line 225)

In practice this distinction results in one group of case managers working alongside families and service users in a collaborative way, whilst the other group work primarily with service users and gather information from and “educate” families while allowing them to express their feelings about the family’s situation.

Case managers’ views on working with families appear to operate independently of whether the case managers have been trained in family interventions or not. These views appear to be personal, formed through prior experience and potentially influenced by growing demands and an unclear organisational message about family inclusion. It brings to question the consistency of case managers’ approaches to family work and how this may impact on the care received by service users and their families.

3. Searching for ecological validity

3a. “BFT ... [is] an additional responsibility, an additional role that I’ve taken on by saying yes I’d like to go on the training” (P002, line 599)

Nine of the case managers interviewed had received BFT training. However, despite viewing BFT as beneficial, their decision to consider formal BFT ultimately came down to their capacity to commit to doing BFT and their confidence in delivering it.

3b. “I suppose every family could benefit from BFT” (P002, line 142)

Trained case managers believed that all families and therefore service users could benefit from formal BFT resulting in BFT being considered as a potential intervention for all service users and their families on their caseloads:

I remember plugging that at first and saying to people it’s not about people that are problems it’s about everybody that’s got psychosis the family should have a good understanding of what’s going on (P006, line 1001)

If you are able to reduce that stress and the problems at home obviously that reduced stress is going to have a positive impact hopefully on the service user which again is going to make your job as a case manager all the more easy (P013, line 249)

However, trained case managers also talked about their role as a case manager conflicting with their role as a BFT therapist. This seemed to result in beliefs that all families benefited from formal BFT being adjusted in practice to accommodate both roles. Trained case managers adopted “ad hoc” BFT for all families, describing formal BFT as secondary to the service user’s mental health:

You are expected to be a jack of all trades ... if you are setting time aside for a specific BFT and a crisis comes up they [crisis] take precedent ... ultimately your case management, case co-ordination role ... takes priority really (P013, line 573)

I don’t feel like there’s a role for like formal family work when the main priority is the young person’s mental health ... that’s not to say in the meantime you wouldn’t have done ... ad hoc bit of stuff (P002, line 329)

The adaptations to case managers approach to BFT (ad hoc) appear to link to their capacity as case managers to adopt an additional role as a BFT therapist.

3c. “You can’t offer any NICE approach if you’ve got that amount of people on your caseload you just can’t do it” (P003, line 635)

Capacity is a complex issue in relation to BFT. Case managers reported insufficient numbers of staff to deliver formal BFT to all families. They also reported that it was difficult to support more than two families alongside their usual caseload. To reconcile this reality with belief about the benefits of BFT, trained case managers used modules from BFT in an “ad hoc” way with all families on their caseload. Formal BFT was therefore generally reserved for families that case managers thought would benefit from more than one aspect of BFT:

I think some of the only barriers like I’ve said are sometimes fitting in times that you can do the work (P004, line 435)

You are usually busy so it's not on your top of priorities if there's something going on (P010, line 231)

You find yourself using a part of BFT just ad hoc ... it might be easier to work with a family in that way because that might be all that they need from BFT ... communication skills in the family might be otherwise ok and there aren't too many arguments or distress in the household ... there are other families that you work with that you think there's quite a few elements of BFT that they would find useful ... in that situation then I would probably think going through the programme (P002, line 145)

3d. "I wasn't necessarily a therapist for the team to sort of use as a BFT therapist"
(P002, line 361)

Considering that trained case managers do not have capacity to use BFT with their own caseload also raised concerns about who was responsible for providing BFT for untrained case managers' caseloads:

I had up to 29 on a caseload which isn't what we are supposed to do and somebody would say ... can you go and work with that family and that family' and you are thinking I beg your pardon you are joking. So it doesn't work (P009, line 626)

So it's like well I'm happy for somebody else to do the BFT with them but I didn't want to go on the training and learn about that myself ... when people have made a referral for BFT ... they've not done much else in thinking about family work because they've thought well they are going to BFT so you know they'll get it all (P002, line 604)

If I had less cases, more time to work with individuals and their families I'd be happy to do BFT more (P005, line 321)

3e. "It does create more work because you are having to see people at certain times of the day obviously being families, people are working and things" (P013, line 281)

With reports of higher caseloads and growing demands from the service it has become dependent on trained case managers' dedication to do BFT. A trained case manager seems autonomous in deciding whether to pickup BFT work alongside their everyday role:

I do additional hours at the moment to incorporate things like BFT as well so that's on top of my normal stuff. (P005, line 28)

It's got to be that self-motivation. (P013, line 487)

This seems to be motivated by benefits they have experienced through working with families using BFT and confidence using the approach.

3f. "I would like to do some co-working to see how it's done, how it's delivered....once I've seen it I can crack on" (P008, line 176)

There are a few trained case managers who, despite regularly using BFT in an ad hoc way, remained unsure about formal BFT or families' perspectives of BFT. These case managers reported not using formal BFT unless they had the opportunity to co-work with someone more experienced. Some had picked up families for BFT following training, but the families had either changed their mind or case managers they co-worked with had decided to continue the work on their own. These case managers seemed less confident about using BFT with families:

Where people are my family on my caseload that I'd like to have it but I'm not going to refer them because it means I've got to do it ... I'd probably help somebody else do their families ... but my own ... too conflicting (P006, line 1273)

I don't always like to do things formally ... with BFT you are asking people to do things that are not normal (P015, line 443)

I can't really say because I've not actually done it ... it's a tool and I pull stuff out of it ... yes I am a bit uncertain (P008, line 215)

Trained case managers' reported that while all families could benefit from BFT, changing demands had adjusted their decision making about offering families formal BFT. If a case manager had no capacity to do formal BFT (i.e. high caseload, crisis) or felt under-confident using formal BFT they reported adopting an ad hoc approach with a family. If

formal BFT was decided upon, the process of selling it to families and the family's decision ultimately determined whether the intervention went ahead:

I'll try and give examples of what other families have been able to gain from it as well. A lot of families will sort of say 'oh we'll give it a go' (P002, line 269).

I've had families that I've felt would benefit from support and from BFT in particular but ... they've felt no we are ok, we are fine it's not something we really want to do. (P004, line 311)

Family refusal does not prevent informal ad hoc work from happening and trained case managers' report inevitably working with families using skills they have learnt through BFT training.

3g. "I think the majority of case managers do a lot more family work than is probably registered" (P014, line 506)

From a service perspective the ad hoc use of BFT becomes problematic because it has not been routinely recorded by case managers; as far as the organisation is aware this work has not happened:

There's a way of capturing it but that's not always the quickest way or just the remembered way or I don't know if it's a uniform way that we would do (P005, line 758)

3h. "I think we know ourselves if someone is going well but we are probably not that very good at communicating it" (P010, line 415)

Another issue that arose was the dissemination of outcomes from BFT work. All case managers who had completed BFT with a family talk in detail about the positive outcomes they have observed or described by families. Unfortunately, standardised outcome measures provided by the service are not routinely used, and family feedback was not recorded. In addition case managers reported not sharing their experiences of formal or ad

hoc BFT with colleagues. It raises questions about whether the benefits of BFT are easy to communicate and the limitations this might have on using outcomes to engineer organisational change. The decision making process of trained case managers seemed different from those who were untrained.

4. Erring on the side of caution

4a. “I don’t know how appropriate they would be for family therapy really 'cause I don’t know what the criteria is” (P007, line 354)

The decision making process about BFT seemed markedly different for untrained case managers. Those interviewed were unaware of any accessible information about BFT and relied on what they had heard from trained case managers. Untrained case managers reported a belief that BFT is beneficial for dysfunctional or difficult families that may otherwise monopolise a case manager’s time or be seen to actively impede on service users wellbeing. Their judgement about who is referred for BFT related to their ability to engage a family; difficult to engage families were often referred for BFT. This seemed to be mediated by the impressions of untrained case managers that BFT might be damaging to the good relationships they had with some families. Capacity also played a significant role in case managers’ decisions to refer for BFT. This related to, their own capacity to work with a family and the capacity of colleagues to carry out BFT.

4b. “People think its crap” (P003, 290)

A predominantly negative opinion of BFT was expressed by untrained case managers. However, some untrained case managers reflected on informal team discussions that provided encouraging information about families’ experiences of BFT. Untrained Case managers referred to BFT as “simplistic” and experienced by families as “patronising”. They reported concerns about families feeling “blamed” or “offended” if they mentioned BFT:

I've heard about it. ... But I'm not sure that the family did benefit that much from it but I'm not sure of what the reasons for that were (P007, line 301)

I don't really have evidence to say it is or it isn't but from what sort of case managers have felt that it's been sort of really useful with some families (P011, line 407)

I would worry about the kind of the patronising kind of sometimes it comes across because it is quite basic stuff (P014, line 67)

Not knowing who BFT is for and concerns untrained case managers reported about BFT resulted in different beliefs about its benefit for service users and families, when compared with the views of trained case managers. The notion that BFT could be perceived as simplistic or critical was not absent from trained case manager interviews, but was mentioned as issues to be explicitly discussed with families when they were introducing the idea of BFT with them.

4c. “I just think they’ve got a false understanding of what BFT is and what it can do that it fixes a problem family” (P006, line 988)

The term “problem families” was predominantly used by BFT trained case managers when discussing untrained case managers’ referrals for BFT. This corresponded with untrained case managers’ descriptions of pronounced systemic difficulties within families that they would consider referring or have referred for BFT. Difficult families were those that case managers had previously had difficulty engaging in general family work:

I think I really struggled to engage with this client and this [BFT] has kind of brought her back in ... re-grouped everybody and it seems like things are a lot more manageable now ... so in that sense it's really helped that family (P014, line 80)

I don't think anything will improve and I am not sure what intervention I will be doing ... I don't know (P001, line 139)

Rather than it actually not working it's probably because a lot of it isn't being delivered or if it is being delivered it's to families that are really, really sort of difficult ... so it's hard to identify any positives that have come out of it (P012, line 540)

4d. “I struggle sometimes engaging how I work with families in terms of not jumping in and sort of saying you are doing this wrong.” (P001, line 233)

Engagement with families seems vital to all case managers’, the time and effort which untrained case managers spent engaging service users’ families could heighten concerns about the impact of mentioning BFT to the family:

I think it is quite difficult to gauge just thinking about you know where they’re up to at the moment, this is all very, very new, probably very sensitive to anything being said in the wrong way (P001, line 236)

I think when you say it to people, family therapy, its sounds a bit like there’s something wrong with you ... it comes across like you are clearly not a good family ... it’s quite difficult to sell it in the right way without offending people (P012, line 252)

I think they would be really defensive ... it depends how they sort of take suggestions like that (P011, line 358)

This investment in working with families and developing a relationship with them appeared to be a barrier to referring a family for BFT because untrained case managers were unsure how families would respond.

4e. “It’s absolutely mentioned but there’s no capacity to do it at the moment” (P001, line184)

Capacity issues from untrained case managers’ perspectives were twofold. When engagement remained difficult or where there was no observable difference in response to the work they had done with families they were more likely to refer them for BFT, as indicated previously. However, there was also the capacity for the service to provide BFT and untrained case managers considered waiting times for families and the impact on their colleagues’ workload if they chose to refer a family:

Might say to someone I think it would be a really good idea for family therapy, it's going to be six months plus before you can get to be seen. If that's needed and if that's at crisis point and they're saying we want to work on it then that's the intervention! (P001, line 290)

You are asking them to do quite a set piece of work on top of their own caseload ... if they had smaller caseloads because they were doing that then I think people would be more open to referring them because they think you know 'well that's part of your role'. (P012, line 334)

This contrasts with the views of some trained case managers who perceived untrained case managers referral of difficult families for BFT as a form of "respite".

4f. "I think some parents just want that space to be able to just off load ... I think there's benefit in that as well" (P001, line 25)

Most untrained case managers worked with families, they offered families information about psychosis and a space to talk about their experience. They also included families in structured work done with the service user. Where communication or family inclusion appeared to impact on a service users' wellbeing this was considered most challenging. Untrained case managers reported often working with complex family dynamics without the support and supervision available to those trained in BFT:

You don't want to obviously make things worse; you don't want to unsettle the family environment. But you know it's important that you get to the root of what's going on (P012, line 90)

I used to think 'oh no' ... for weeks and weeks and not in a formal sort of family therapy but I suppose that's what we were doing ... it would be quite negative and everything that we were sort of trying to suggest ... would always be shut down really quickly. But it's just a slow process of making everyone feel comfortable (P011, line 288).

Untrained case managers also reported struggling to record the work that they did with families in a way that was recognised by their employing organisation and did not disseminate their work. When families declined offers of BFT or case managers were

uncomfortable talking to families about BFT, families did not receive ad hoc BFT.

Untrained case managers reported continuing general work with families as part of their role.

5. Oppressed rebellion

5a. “I can understand that something like that is a great tool if you are unskilled and I mean that in the nicest way” (P009, line 165)

In addition to the case managers already discussed there were two case managers who expressed a different perspective. One trained in an alternative family intervention to BFT and both case managers had received BFT training and objected to using the approach. BFT was considered insulting to their current level of training and established ability to work with families. Both case managers had experience working in EIS for over six years⁶. These case managers never referred families for BFT but consistently worked with families using their own approach outside of the support offered to BFT trained case managers. For alternatively trained and ‘objecting’ case managers BFT seemed symbolic of how the service devalued their existing skills and competencies. They did not view BFT as a good enough approach to benefit the population EIS work with:

What on earth have I been doing all these years, so I found it [BFT] vaguely offensive (P009, line 69)

If we are offering family work you are basically referring to BFT now to me ... if that’s the only option for a lot of the families that we work with that is not what they need (P003, line 406)

5b. “You get some fantastic band 5s and some not so good 6s and you get some appalling 7s and upwards”. (P009, line, 6)

The alternatively trained and objecting case managers considered their skills devalued due to their role and banding. A lot of frustration seemed to be directed at the inequality

⁶ Further elaboration on P003 and P009’s characteristics have been omitted to maintain anonymity

between case managers and psychologists who started at a higher pay band but did not carry a caseload. Clinical psychologists conducted a lot of training in the service for and alongside case managers and had often led the BFT training and supervision groups.

I feel that what needs to be done is to remove all this I am therapist, I am a nurse, I am a social worker, I am a psychologist ... we are all going out and we are all doing therapy under different headings ... we all need to be in there [spoke team] at the same level (P009, line 506)

Other people thought yes that's the right way to progress [advising] I don't know how it's going to progress but yes do it go with it ... that's what the psychologist themselves do, if they are not sure on an area they go to somebody... get that supervision from them. Well that's just what I've been doing but it felt like well because you're not [a psychologist] then we can't say it's that (P003, line 765)

We were not asked we were told, this is what we've [psychology department] decided ... I don't particularly enjoy that sort of dictation (P009, line 271)

Both case managers viewed family work as integral to their role and report positive outcomes from the work that have done with service users and families on their caseloads, citing discharge to general practitioners' (GP) management and limited relapse for people on their caseload as evidence.

The way in which participating case managers made decisions about BFT was influenced by a number of factors. Five themes emerged from the data, the contents of which were determined largely by training status, previous experience and organisational challenges.

Discussion

In summary, this research supports previous findings that the organisational context and case manager's views and beliefs form the basis for and can become a barrier to the routine implementation of family interventions (Fadden et al., 2011; Eassom et al., 2015).

Case managers trained in BFT appeared to provide a service for families by incorporating BFT into their every-day skills. They also described using these skills regularly with

families. Trained case managers who remained under confident following BFT training predominantly worked in this way and had not completed any formal BFT since being trained. Three trained case managers who seemed particularly motivated to provide formal BFT had reported the largest number of completed formal BFT interventions when compared to other trained case managers. One case managers had talked about using their own time to ensure families received BFT. This related to research findings indicating a small group, within a larger group of BFT trained clinicians tend to demonstrate more motivation to carryout BFT with families (Fadden, Heelis & Bisnauth, 2010). This indicates that the translation of BFT training into practice could be mediated by the individual characteristics of case managers.

For trained case managers there seemed to be a fundamental belief that BFT could benefit all families. However, their role as a BFT therapist was viewed as separate and secondary to case management. They based their decisions about formal or ad hoc BFT upon their personal judgements about families' communication and expressed needs. They offered formal BFT to families who they thought would benefit from a number of components of BFT. This decision to ration formal BFT to a few 'eligible' families was further influenced by case managers' available time to carry out formal BFT. High caseloads had also significantly reduced the number of families offered formal BFT in practice. However, BFT trained case managers' adaptation of BFT, using it "ad hoc" countered the absence of intervention due to capacity constraints. Ad hoc BFT enabled more families to receive brief interventions to meet their needs.

BFT trained case managers reported not recording ad hoc BFT or evaluating their work with families in a formal way. This reduced the likelihood of disseminating any benefits from formal BFT within the service and to the organisation. It was also difficult to assess whether ad hoc use of BFT skills is an effective use of this intervention.

Untrained case managers believed that BFT was reserved for difficult families who needed support with problematic family dynamics. This message seemed to be supported by the service. Case managers talked about BFT being suggested as a possible intervention in “reds” meetings where complex and difficult cases would be discussed. This mirrors findings from previous research indicating that organisations and services maintaining a message that BFT is only for difficult families is counterproductive and stigmatising (Fadden et al., 2006; Fadden et al., 2011).

Untrained case managers also described regularly working with families and only considering BFT where they had not been able to engage with or alter family dynamics themselves. They often described very stressful incidents and continuous struggles to engage families which seemed unsupported beyond general team discussions and venting frustrations informally. Untrained case managers also reported limited recording of the family work they carried out, indicating that the service and wider organisation is not clearly informed about the amount of family work happening or its impact on service outcomes. Where untrained case managers had managed to engage and elicit change with families they described a reluctance to offer BFT, citing concerns about the negative this could have on their current engagement with a family. Untrained case managers would consider offering BFT if they no longer had capacity to meet a family’s expressed needs due to other demands. However, further barriers such as waiting lists, the demands they would be making on colleagues’ time as well as limited confidence “selling” BFT to families often prevented referrals being made. BFT was predominantly not offered unless all other avenues had been exhausted.

Not receiving information about the benefits families and case managers experienced from using BFT or a clear rationale for referral for BFT seemed to maintain difficulties described by untrained case managers.

Although different, both trained and untrained case manager's decision making processes are influenced by capacity. Capacity constraints ultimately limited families' choice about formal BFT, delayed or excluded families from access to BFT and increased the likelihood that offering BFT would be received as stigmatising.

Case managers trained in alternative family interventions or who objected to BFT; felt their experience superseded the need to use a BFT approach. They felt BFT was the only family intervention recognised by the service and never referred families for BFT, working instead with families by tailoring their skills and alternative training to families' needs. Both case managers worked regularly with families and reported good idiosyncratic outcomes from their work. They felt unsupported by the wider team when they had voiced their opinions about family interventions. While a rift between BFT trained and untrained case managers had been evident from other interviews, for these two case managers a rift between case managers and psychology was more pronounced. They specifically voiced the difference in perceived status, pay and workload describing having greater responsibility with comparable skills.

Recommendations

The way in which decisions are made about formal family interventions is varied and subjective. This creates a lottery system in terms of what families are offered and receive from EIS. It is recommended that a systematic, objective method of consulting families and identifying their intervention needs is used routinely. In addition, resources need to be focussed on the delivery of ad hoc and formal BFT. It is also clear that these efforts should be recorded, evaluated and valued as core EIS activities. Incorporating a decision making tool, like the Relatives Urgent Needs Schedule (RUNS) into standard practice when families' first access services could assist and identify family intervention needs and a

clear pathway of care for individual families (Mulligan, Sellwood, Reid, Riddell & Andy, 2013).

The introduction of BFT training appears to have enhanced family work carried out in this EIS. However, without dissemination of results, clear outcomes or measurement of all family work and intervention happening within the service it is difficult to know whether this has improved the experience, well being or mental health of families and services users. Equally, it is unclear if using family interventions has assisted case managers' roles by reducing demands over time. Case managers describe BFT as a fading approach within the service because it is not mentioned or featured on rolling agendas. Case managers current demands do not allow time for this additional responsibility or indeed the practice of formal BFT with families as the Meriden programme has attempted to challenge (Fadden et al., 2011). A clearer family intervention pathway for all service users and their families; overseen by specialist team members, receiving a reduced caseload to allow for this responsibility to be maintained, seems vital.

Ensuring that all case managers are trained in family interventions also seems to be vital in bringing the EIS teams together and making family interventions everybody's responsibility. There are multiple approaches to family intervention and more experienced practitioners may benefit from open discussions about using BFT flexibly and tailoring it to individual family needs. BFT was designed as a basic tool to enable clinicians to feel confident working with families using basic but effective skills (Fadden, 2006). EIS case managers are already very skilled in using CBT approaches in their everyday work. All case managers interviewed shared the goal of providing the best possible interventions for service users. While there was disagreement about what constitutes this, it is conceivable that reinforcing the message that BFT can and should be adapted to individual family need could help reunite the different perspectives in this service.

Limitations

The research was completed as a component of a Doctorate in Clinical Psychology and time-limited in line with the aims and requirements of training. Therefore independent review of the analysis was not pursued. To address this limitation supervision acted as a proxy where the researcher's perspective was discussed and challenged.

The sample may not represent how decision making about BFT happens across the service. This research instead offers insight into how the participating case managers make decisions about offering BFT as part of their practice.

Despite the researcher's efforts to remain neutral, some case managers apologised about expressing a negative perspective of BFT following their interviews. This indicates that despite appearing candid at times, participants' responses may have been influenced by perceived expectations of the researcher.

It must be born in mind that the findings of this research are limited to a small sample from a narrow population and therefore cannot be generalised. In addition, qualitative data can be interpreted using a number of different methods and an alternative approach could elicit variations to the interpretations that have been presented.

Future research

A key focus for future research will be development and evaluation of education of not only case managers of those affected by early psychosis, but also senior managers and clinicians who are responsible for ensuring that evidence based practice is implemented. Resources aside, given the commitment to BFT demonstrated by the service, why have members of staff still not understood the value of the intervention? A better understanding of outcomes of family interventions in clinical practice and the experience of families, who

engage, disengage or refuse family interventions for psychosis could inform case managers and services about family's intervention needs and inform better practice.

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Appendices

Appendix 1

Literature Review: Author guidelines Clinical Psychology Review

No word limit specified, but clinical psychology review publishes papers up to 10,000 words.

Authors names, statements and highlights have been omitted as considered not necessary for the purpose of Thesis examination.

APA sixth edition format

Title. Concise and informative. Titles are often used in information-retrieval systems. Avoid abbreviations and formulae where possible.

Abstract

A concise and factual abstract is required (not exceeding 200 words). This should be typed on a separate page following the title page. The abstract should state briefly the purpose of the research, the principal results and major conclusions. An abstract is often presented separate from the article, so it must be able to stand alone. References should therefore be avoided, but if essential, they must be cited in full, without reference to the reference list.

Keywords

Immediately after the abstract, provide a maximum of 6 keywords, using American spelling and avoiding general and plural terms and multiple concepts (avoid, for example, 'and', 'of'). Be sparing with abbreviations: only abbreviations firmly established in the field may be eligible. These keywords will be used for indexing purposes.

Abbreviations

Define abbreviations that are not standard in this field in a footnote to be placed on the first page of the article. Such abbreviations that are unavoidable in the abstract must be defined at their first mention there, as well as in the footnote. Ensure consistency of abbreviations throughout the article.

Acknowledgements

Collate acknowledgements in a separate section at the end of the article before the references and do not, therefore, include them on the title page, as a footnote to the title or otherwise. List here those individuals who provided help during the research (e.g., providing language help, writing assistance or proof reading the article, etc.).

Footnotes

Footnotes should be used sparingly. Number them consecutively throughout the article. Many word processors can build footnotes into the text, and this feature may be used. Otherwise, please indicate the position of footnotes in the text and list the footnotes themselves separately at the end of the article. Do not include footnotes in the Reference list.

Electronic artwork

General points

- Make sure you use uniform lettering and sizing of your original artwork.
- Embed the used fonts if the application provides that option.
- Aim to use the following fonts in your illustrations: Arial, Courier, Times New Roman, Symbol, or use fonts that look similar.
- Number the illustrations according to their sequence in the text.
- Use a logical naming convention for your artwork files.
- Provide captions to illustrations separately.

Size the illustrations close to the desired dimensions of the published version.

Submit each illustration as a separate file.

Figure captions

Ensure that each illustration has a caption. Supply captions separately, not attached to the figure. A caption should comprise a brief title (**not** on the figure itself) and a description of the illustration. Keep text in the illustrations themselves to a minimum but explain all symbols and abbreviations used.

Tables

Please submit tables as editable text and not as images. Tables can be placed either next to the relevant text in the article, or on separate page(s) at the end. Number tables consecutively in accordance with their appearance in the text and place any table notes below the table body. Be sparing in the use of tables and ensure that the data presented in them do not duplicate results described elsewhere in the article. Please avoid using vertical rules.

References

Citations in the text should follow the referencing style used by the American Psychological Association. You are referred to the Publication Manual of the American Psychological Association,

Appendix 2

Literature Review

A table listing the chronological order adhered to for phase 3 repeated reading for meta-synthesis.

Order	Year of publication	First Author
1	1997	Tuck et al
2	2001 (January)	Barker
3	2001 (August)	Czuchta et al.
4	2003	Schultze et al.
5	2005	Sin et al.
6	2006:	Monteiro et al.
7	2007 (April)	Wong et al.
8	2007 (August)	Corcoran et al.
9	2008 (June)	Sin et al.
10	2008 (November)	Bergner et al.
11	2009 (June)	Gerson et al.
12	2009 (December)	Penny
13	2010 (May)	Nordby et al.
14	2010 (June)	Franz et al
15	2011 (January)	Cadario et al.
16	2011a (March)	McCann et al.
17	2011b (May)	McCann et al.
18	2011c (May)	McCann et al
19	2011d (September)	McCann et al.
20	2011 (September)	Tanskanen et al.
21	2012	Sin at al.
22	2014 (June) in press	Connor et al
23	2015	Wainwright et al.

Appendix 3

Literature Review: Development of Phase 6

Phase 6: Themes developed from synthesis

1. Systemic identity: understanding everything that existed before

Identity	Knowledge	Culture	Society & Media
Normal & happy child; social; sensitive; high expectations; plans for the future; positive future; developed relationships & roles; Family identity; relational bonds	Vagueness & confusion about mental health; negative ideas of mental health systems; lack of awareness.	Clear beliefs; future perceptions; spiritual beliefs & explanations for negative experience.	Images of a Looney bin, violence & danger; not normal; social distance; stigma & unhelpful portrayals; negative views

2. Maintaining the status quo in the face of change

Noticing changes	Acceptable explanations	Hidden fear
Observable gradual changes; broad range of symptoms; vague & hard to define.	adolescence; stress; school; drugs; relational betrayals; depressed; passing phase	Hidden intuition; internal reasoning & persuasion (it can't be); denying problem i.e. difficulties noticed in retrospect

3. Systemic Implosion: overwhelmed by duration & crisis

Progression into Crisis	Struggling to cope
Alarming behaviour; severe symptoms & dangerous incidents; legal encounters; overwhelmed coping strategies; changeling; unrecognisable; fears of & for person;	Self sacrifice; fear; confusion; uncertainty; searching for meaning; bewildered; disruption; socially distanced, reluctance to engage; worry for family members; fruitlessly pushing for change; frustration; anger; denial; informal help seeking.

4. Navigating a labyrinth of incongruent help and support: searching for answers

Inconsistent professional contact and access	Answers & meaning	Emotional impact
Relief; hope & compassion; respectful; resourceful; prompt; taken seriously; reassuring; sensitive; difficulties scheduling appointments; no choice; communication difficulties; perceived incompetence; questioning family; varied explanations & advice; school social workers helpful; emergency admissions problematic but necessary; inpatient services insensitive or unavailable; little information; long process; multiple services; denial of access; need to be convincingly unwell; unresponsive; unfathomable & evasive.	Diagnostic ambiguities; chronic nature poor prognosis no clear cause or cure; need to understand meaning; more questions; left to own interpretation; labelling; Helpful medication but side effects.	Changed lives; loss; blamed; awful to witness; rejected; frustration; worries; trauma; guilt; shame; isolation; discomfort; continuation of struggle; Grateful for containment; frustrating; fear; distrust; uncertainty.

5. Three degrees of separation vs. three degrees of influence: working together or working apart

What families/carers receive	What they want	The impact of caring
Valuable support; deficits in quality of care; Service limitations; difficult to access psychology & community care; exclusion; fragmented care; financial burden; kept in the dark; over optimistic or pessimistic narratives; having to seek out information; confidentiality used as a shield or lazy fallback; positioned as an enemy.	Early support; realistic information & knowledge; individual care for loved one; valued & listened to; services bridging activity; support initiating engagement; support adjusting; inclusion & involvement; practical advice; consistent communication; support with stigma; separate appropriate support for siblings; signposting.	Fluctuation of symptoms affect perceptions; coping & adapting is ongoing; struggle to understand & come to terms with complexity; fragile & sensitive households; arguments & frustrations; caught between services & loved one; eventual acceptance; steep learning curve; resentful; worries for whole family; constant worry.

Appendix 4

Empirical Paper: Author Guidelines

Journal of occupational and organisational psychology overview of author guidelines

The Journal of Occupational and Organizational Psychology publishes empirical and conceptual papers which aim to increase understanding of people and organizations at work. Its domain is broad, covering industrial, organizational, engineering, vocational and personnel psychology, as well as behavioral and cognitive aspects of industrial relations, ergonomics, human factors and industrial sociology. Innovative or interdisciplinary approaches with a psychological emphasis are particularly welcome. So are papers which develop the links between occupational/organizational psychology and other areas of the discipline, such as social and cognitive psychology.

We welcome the following varieties of paper:

- empirical research papers, containing new quantitative or qualitative data which address significant theoretical and/or practical concerns;
- papers which offer new theory and conceptualization, perhaps accompanied by a critique of existing approaches;
- narrative and/or quantitative reviews of existing research which lead to new conclusions or insights into a field of research and/or practice;
- prescriptive articles advocating changes in research paradigms, methods, or data analytic techniques;
- analyses of practice in occupational and organizational psychology, where such analyses are driven by theory and/or sound data.

1. Circulation

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

2. Length

The word limit for papers submitted for consideration is 8000 words. The word limit does not include abstract, references, figures, and tables. Appendices however are included in the word limit.

4. Manuscript requirements

- Contributions must be typed in double spacing with wide margins. All sheets must be numbered.
- Manuscripts should be preceded by a title page which includes a full list of authors and their affiliations, as well as the corresponding author's contact details.
- All articles should be preceded by an Abstract of between 100 and 200 words, giving a concise statement of the intention, results or conclusions of the article. The abstract should not include any sub-headings.

- All articles must include Practitioner Points – these are 2-4 bullet points, following the abstract, with the heading ‘Practitioner Points’. These should briefly and clearly outline the relevance of your research to professional practice. (Please include the ‘Practitioner Points’ in your main document but do not submit them to Editorial Manager with your abstract.)
- The main document must be anonymous. Please do not mention the authors’ names or affiliations (including in the Method section) and always refer to any previous work in the third person.
- Tables should be typed in double spacing, each on a separate page with a self-explanatory title. Tables should be comprehensible without reference to the text. They should be placed at the end of the manuscript but they must be mentioned in the text.
- Figures can be included at the end of the document or attached as separate files, carefully labelled with symbols in a form consistent with text use. Unnecessary background patterns, lines and shading should be avoided. Captions should be listed on a separate sheet. The resolution of digital images must be at least 300 dpi. All figures must be mentioned in the text.
- All articles should contain a clear statement of where and when any data were collected.
- For reference citations, please use APA style. Particular care should be taken to ensure that references are accurate and complete. Give all journal titles in full and provide doi numbers where possible for journal articles. For example:

Author, A., Author, B., & Author, C. (1995). *Title of book*. City, Country: Publisher.
Author, A. (2013). Title of journal article. *Name of journal*, 1, 1-16. doi:
10.1111/bjep.12031
- SI units must be used for all measurements, rounded off to practical values if appropriate, with the imperial equivalent in parentheses.
- In normal circumstances, effect size should be incorporated.
- Authors are requested to avoid the use of sexist language.
- Authors are responsible for acquiring written permission to publish lengthy quotations, illustrations, etc. for which they do not own copyright.

Appendix 5: Participant Information Sheet and Consent form



Behavioural family therapy: enablers and barriers in practice.

Participant Information 01.05.2014 Version 1.

You are being invited to participate in a research study. Before you decide whether to participate, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and feel free to ask us if you would like more information or if there is anything that you do not understand. We would like to stress that you do not have to accept this invitation and should only agree to take part if you want to.

Thank you for reading this.

1. What is the purpose of the study?

Research has indicated that behavioural family therapy can be an effective intervention for service users and families engaged in early intervention services. This research aims to understand more about behavioural family therapy in practice.

2. Why have I been chosen to take part?

To better understand the role of behavioural family therapy in practice this research aims to interview 15 case managers who may be trained in behavioural family therapy, have co-worked with someone delivering behavioural family therapy or have no practical experience of behavioural family therapy. Your understanding of the service and the service users who engage with the service is key to this research. It would be really helpful to understand your view of behavioural family therapy, its value within an early intervention service and how it influences or affects your role.

3. Do I have to take part?

Participation in this research is voluntary and you are under no obligation to participate. Taking part in this research is your choice.

4. What will happen if I take part?

Participating in this research would involve being interviewed by Christine Day who is the researcher for this study. The interviews are designed to understand your perspective and are not a test of your knowledge about behavioural family therapy; it does not matter if you do not know anything about behavioural family therapy or if you have positive or negative feelings about this approach. It is important for us to understand the reality of using behavioural family therapy in practice and all perspectives are valuable and will support the research to achieve its aim.

If you decide to participate a time and place for the interview will be arranged with Christine Day. You will be asked to participate in one interview which will last approximately one hour. The interview will be recorded on a digital recorder and the recordings will be stored electronically in password protected files. The interviews will then be transcribed and any identifiable information will be removed from the transcripts. The researcher and transcribers will be the only people who have access to the recordings and the transcripts will be analysed by the researcher with support from supervisors.

5. Expenses and / or payments

We realise that your time is precious and would therefore like to compensate you for the time you give up to participate in this research. Therefore all participants will receive a £10 gift voucher following participation in the study. You will have a choice of gift voucher you would like to receive and the researcher will ask you about this when you are arranging the interview.

6. Are there any risks in taking part?

There are no obvious risks to participating in this research. However you may feel uncomfortable talking to someone openly about your opinion of behavioural family therapy or it could bring up experiences of stress relating to the pressure of a case managers role in the NHS. If this occurs it will be approached sensitively by the researcher who is experienced in interviewing.

7. Are there any benefits in taking part?

Participating in this research gives participants an opportunity to speak openly about behavioural family therapy and talk about their experience confidentially. This research will be presented back to the service and written for publication (all participants will be

anonymous and the interviews collated into themes). It is an opportunity to influence practice and the evidence base by allowing us to understand your perspective.

8. What if I am unhappy or if there is a problem?

If you are unhappy, or if there is a problem, please feel free to let us know by contacting Dr William Sellwood 0151 794 5081, Sellwood@liverpool.ac.uk and we will try to help. If you remain unhappy or have a complaint which you feel you cannot come to us with then you should contact the Research Governance Officer at ethics@liv.ac.uk. When contacting the Research Governance Officer, please provide details of the name or description of the study (so that it can be identified), the researcher(s) involved, and the details of the complaint you wish to make.

9. Will my participation be kept confidential?

All data collected will be stored electronically on a secure password protected computer drive at the University of Liverpool and which is only accessible to the researcher for this study. You will be asked not mention your name or identifiable information during the interview and anything that would be identifiable will be removed when the interviews are transcribed. All copies of the interview transcripts will be anonymous, password protected and stored on a password protected computer drive at the University of Liverpool. Data will be stored at the University of Liverpool for 10 years by Dr William Sellwood and then destroyed.

10. What will happen to the results of the study?

When the data from the interviews has been collated, analysed it will be written up as a research paper for publication. This will form part of the researcher's thesis for examination on the doctorate of clinical psychology at the University of Liverpool. It will also be submitted for publication to an appropriate peer review journal. The researcher will come back to the service and feedback the findings of the research.

11. What will happen if I want to stop taking part?

All participants are free to withdraw from the research at any time. To do this you would need to contact the researcher or a member of the research team to let them know you wish to withdraw. However where data has already been anonymised it may become difficult to identify your data and we would not be able to identify and remove your data from the analysis at this stage.

12. Who can I contact if I have further questions?

Christine Day (researcher) Email: Christine.day@liverpool.ac.uk, Tel: 0151 794 5081

Doctorate of Clinical psychology

University of Liverpool

Institute of Psychology, Health and Society

Whelan Building

Brownlow Hill

Liverpool

L69 3GB

PARTICIPANT CONSENT FORM 01.05.2014 Version 1.

Title of Research Project: Behavioural family therapy: enablers and barriers in practice.

Researcher(s): Christine Day

**Please initial
box**

1. I confirm that I have read and have understood the information sheet dated 01.05.2014 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my rights being affected. In addition, should I not wish to answer any particular question or questions, I am free to decline.
3. I understand that, under the Data Protection Act, I can at any time ask for access to the information I provide and I can also request the destruction of that information if I wish.
4. I understand that the interview will be recorded and consent to this.
4. I agree to take part in the above study.

Participant Name

Date

Signature

Researcher

Date

Signature

Principal Investigator:

Dr William Sellwood

University of Liverpool, Whelan Building

Brownlow Hill, Liverpool L69 3GB

0151 794 5081

sellwood@liverpool.ac.uk

Student Researcher:

Christine Day

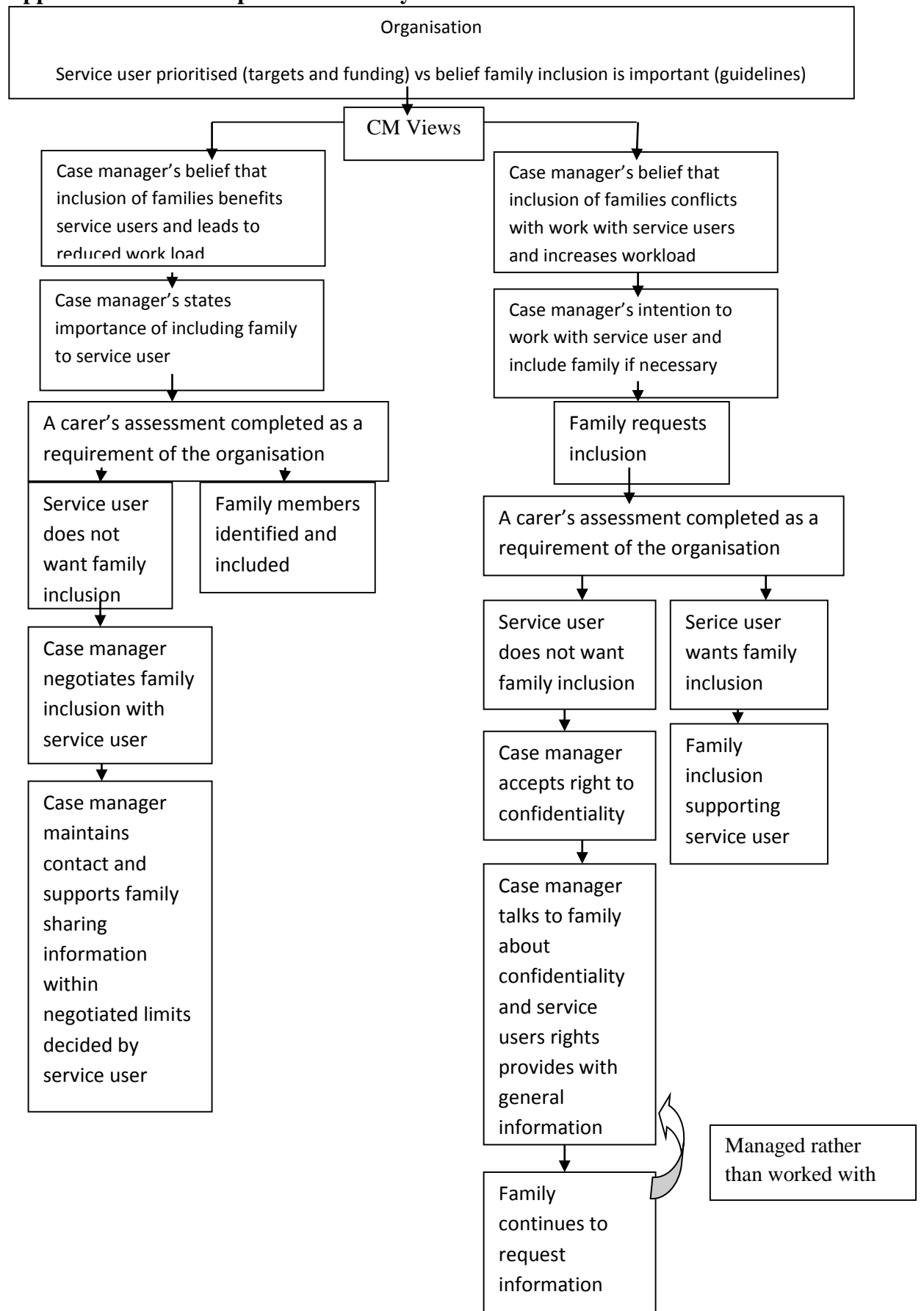
University of Liverpool, Whelan Building

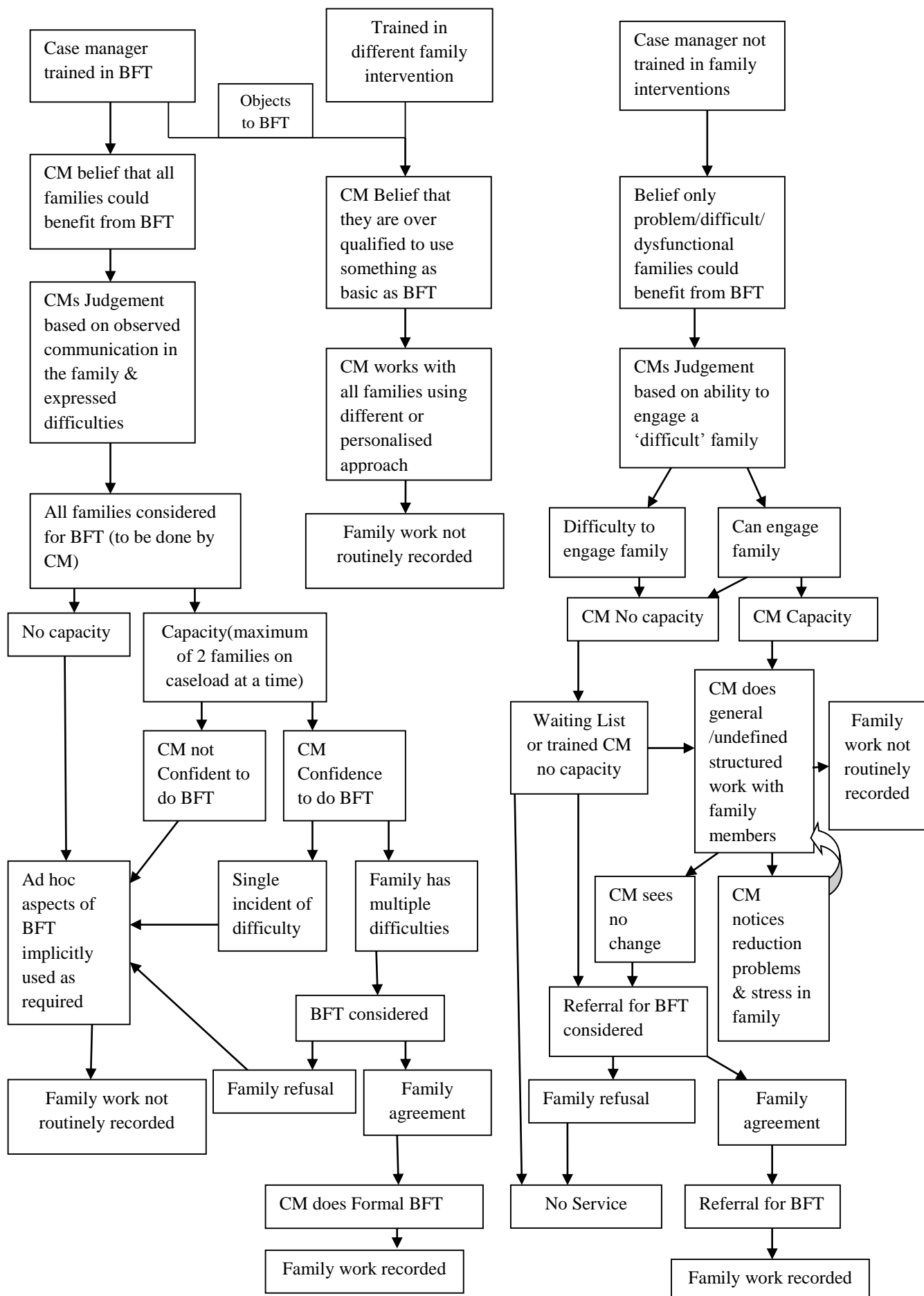
Brownlow Hill, Liverpool L69 3GB

0151 794 5081

Christine.day@liverpool.ac.uk

Appendix 6 : Final templates from analysis





Appendix 7: An example of the evolving template of case manager and team perspectives of Behavioural Family Therapy (BFT)

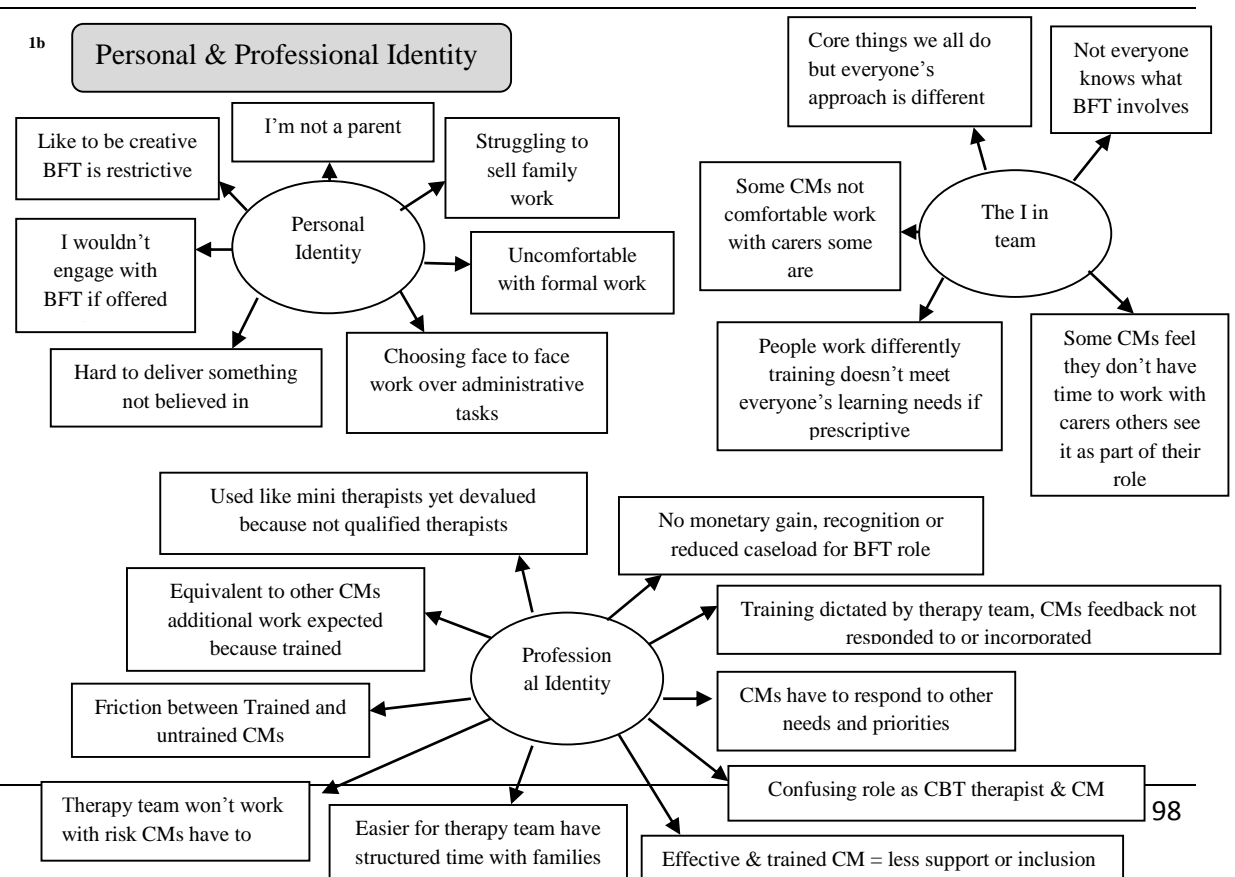
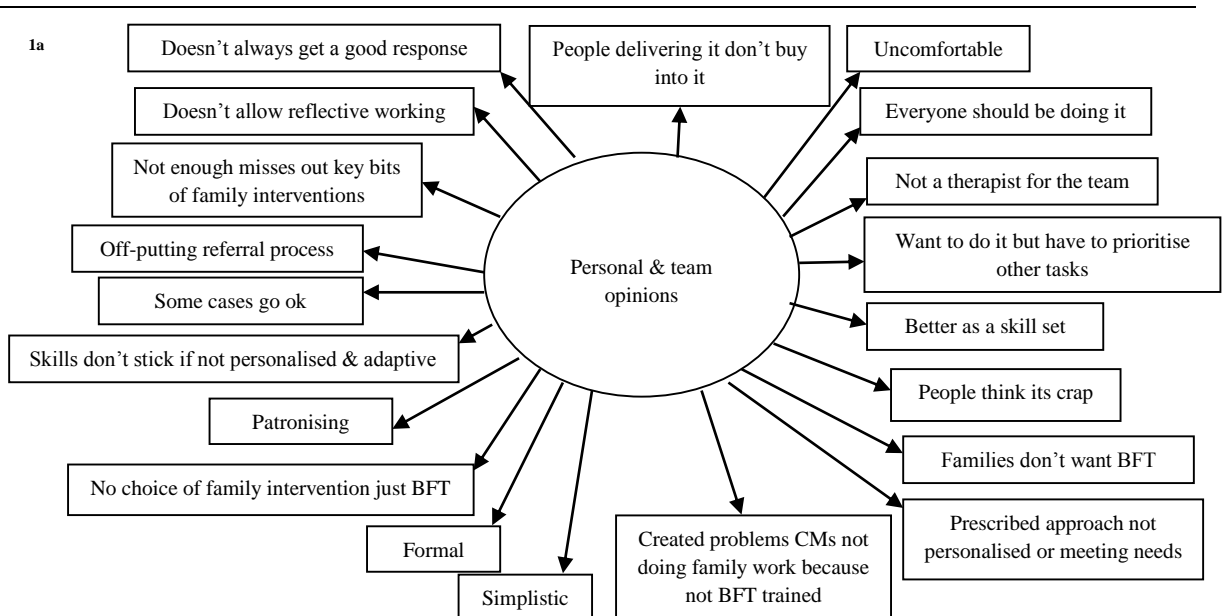
The initial template started as a mind map/brain storm of case managers' narratives. This example shows the early codes of personal and team opinions of BFT and how this was broken down into concepts relating to personal and professional identity and differences within the team.

1

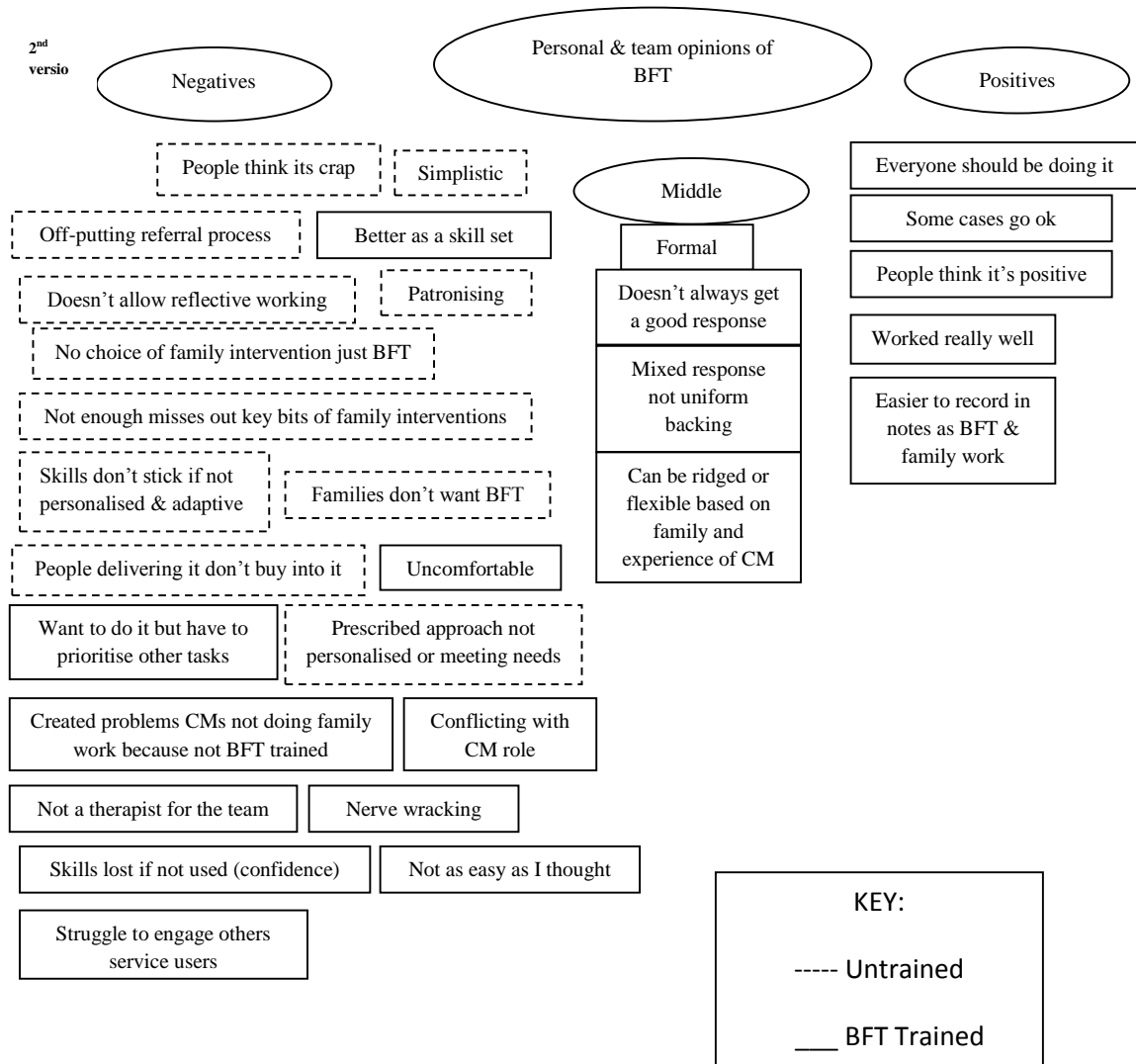
Decision making: case manager and their view of the teams perspectives:

(a) Personal & Team opinion of BFT

(b) Personal & Professional Identity



Following the coding and analysis of additional interviews the codes developed into negative, neutral and positive perspectives and it became apparent the differences of opinion were related to training and/or experience and that the majority of case managers trained in BFT used positive or neutral descriptions as opposed the case managers who had no family work/BFT training who reported negative individual perspectives. Disconfirming cases seemed related to alternative training and professional identity.



3rd version

This developed coding that understood decision making as related to case manager's perspectives related to their training and experience.

BFT Trained	Untrained	CBT FI training/objects (P003 & P009)
Professional identity (lost)	Professional identity (ignored)	Professional identity (persecutory use)
Logistically Challenging	Cautious about families response and clinical consequences	Restrictive approach
Team Split	Manualised and restrictive	Not suitable for service users
Confident = want to do more and motivated	Not what families want	
Not confident = ad hoc work	Blaming	

Appendix 8: Excerpt of reflective diary.

The following excerpts from my reflective diary are an example of the supervisory process and how my personal reflections were discussed utilised in supervision.

Topic: Logistics and teams

... At this point the interviews seem varied and at times confusing, each case manager's opinion seems inconsistent with another's and I have noticed differences in logistical details described by each case manager. I wonder if there are actual differences between spoke teams and how they manage behavioural family therapy referrals (BFT), or if they are also confused about the process of referring someone for BFT. At times it feels like it may be an excuse for not doing BFT I find myself feeling perhaps unfairly critical of some of the case manager's responses, they feel like excuses and I am concerned my inner criticism is affecting the interviews. Listening back to the first few interviews my style has improved and I sound like I am getting alongside participants but still challenging and trying to understand, there are times I stop asking and I recall feeling uncomfortable like I have probed to much however listening back to the interviews it does not sound this way and perhaps my novice at this style of interviewing is impacting on my judgement of dynamics in the room....

Supervision meeting with Dr Helen Lockett 3rd of February 2015:

(Helen is my external supervisor who works as a clinical psychologist and BFT lead for the service. Although I do not discuss any specifics about individual interviews or interviewees I bring questions about logistics and overarching queries to our supervision)

Following supervision with Helen it became clear that each spoke team has different demands regarding BFT referrals. Each team has a waiting list with different waiting times (North: on hold as no capacity; Central: 6 months waiting time; East: no referrals so no waiting list). There is no consistency across the service; each spoke approach is designed to meet the needs of their geographical area. This feels like it accounts for a lot of my confusion and adds some clarity to what remains confusing for me, which I imagine is confusing for case managers (?) but this could be because I am confused looking from the outside in ... this topic needs further exploration in the next interviews.

It is also clarified that BFT trained case managers will generally work with families they refer for BFT and referrals from case managers who are not trained in BFT will go onto a waiting list.

Supervision Meeting with Prof. Elizabeth Perkins Friday 6th February 2015

(Liz is my primary internal supervisor, she is an experienced qualitative researcher and provides supervision for my interviews, coding and interpretation of the data)

Today I brought my confusion to supervision and the clarification of differences across teams from my supervision with Helen. Liz wanted to know why I thought they were a

team and what it is that makes them a team. I considered them as a team mainly as this is how they are referred to (spoke teams) but had not thought about the meaning and concept of a team and what this actually meant. We explored when they worked together and established that they appeared to be more like individual practitioners who were based in the same building. They often had planned meetings and discussions together and would at times co-work however the majority of their roles as case managers involved individual work/supervision/management regarding their own caseload.

There seems to be layers: from the overarching organisation; then the service message; the spoke practice and the manager's interpretation of this followed by the individual practitioners professional and personal identity and how their beliefs and judgements about BFT are put into practice ... Questions for future interviews should query the concept of them being a team and professional and personal identity and how this influences practice also needs further exploration. Perhaps the confusion is about my perspective of them as a unified team and this is not the case and this categorisation case manager" is meaningless in this respect because it is such a varied role and very individual. Definite "I" in team.

These brief excerpts are examples of how my reflective diary was used throughout the research process. I spent time going back through my reflective diary and moving my reflections forward alongside the evolving templates and coding of each interview.