

**KEY-ELEMENTS OF FAMILY INTERVENTIONS FOR
PSYCHOSIS: A QUALITATIVE RESEARCH**

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*In memory of my father,
he was an example for me,
in showing that one should be human above all.*

ABSTRACT

Background: Psychotic-spectrum disorders are complex biopsychosocial conditions and family issues are important determinants of prognosis. The discovery of the influence of expressed emotion on the course of schizophrenia paved the road to the development of family interventions aiming to lower the “emotional temperature” in the family. These treatment approaches became widely recognised. Effectiveness studies showed remarkable and strong results in relapse prevention and these interventions were generalised to other psychotic disorders besides schizophrenia. Family interventions for psychosis (FIP) prospered and were included in the most important treatment guidelines. However, there was little knowledge about the process of FIP. Different FIP approaches all led to similar outcomes. This intriguing fact caught the attention of authors and attempts were made to identify the key-elements of FIP. Notwithstanding, these efforts were mainly based on experts’ opinions and the conclusions were scanty. Therefore, the knowledge about the process of FIP remains unclear.

Aims: To find out which are the key-elements of FIP based on empirical data.

Methods: Qualitative research. Three studies were conducted to explore the process of FIP and isolate variables that allowed the identification of the key-elements of FIP. Study 1 consisted of a systematic literature review of studies evaluating process-related variables of FIP. Study 2 subjected the intervention records of a formerly conducted effective clinical trial of FIP to a qualitative analysis. Records were analysed into categories and the emerging data were explored using descriptive statistics and generalised estimating equations. Study 3 consisted of a narrative evaluation using an inductive qualitative approach, examining the same data of Study 2. Emotional markers

and markers of change were identified in the records and the content of these excerpts was synthesised and discussed.

Results: On Study 1, searches revealed 733 results and 22 papers were included in the qualitative synthesis. We found a single study comprehensively exploring the process of FIP. All other studies focused on particular aspects of the process-related variables. The key-elements of FIP seemed to be the so-called “common therapeutic factors”, followed by education about the illness and coping skills training. Other elements were also identified, as the majority of studies evidenced a multiple array of components. Study 2, revealed as the most used strategies in the intervention programme we analysed: the addressing of needs; sharing; coping skills and advice; emotional support; dealing with overinvolvement; and reframing relatives’ views about patients’ behaviours. Patterns of the usefulness of the strategies throughout the intervention programme were identified and differences between high expressed emotion and low expressed emotion relatives were elucidated. Study 3 accumulated evidence that relatives experience different emotions during group sessions, ranging from anger to grief, and later on, to acceptance and positive feelings.

Discussion: Study 1 suggested a stepped model of intervention according to the needs of the families. It also revealed a gap in qualitative research of FIP. Study 2 demonstrated that therapists of the trial under analysis often created opportunities for relatives to express and share their concerns throughout the entire treatment programme. The use of this strategy was immediately followed by coping skills enhancement, advice and emotional support. Strategies aiming to deal with overinvolvement may also occur early in the treatment programme. Reframing was the next most used strategy, followed by dealing with anger, conflict and rejection. This middle and later work seems to operate in lowering criticism and hostility, while the former seems to diminish

overinvolvement. Single-family sessions may be used to augment the work developed in the relatives groups. Study 3 revealed a missing part of Study 2. It demonstrated that the process of FIP promotes emotional changes in the relatives and therapists must be sensitive to the emotional pathway of each participant in the group.

Key-Words: Family interventions; psychoeducation; psychosis; process; elements; qualitative research.

PREFACE

When I started to run groups for relatives of persons suffering from psychosis, ten years ago, I knew almost nothing about this subject. I read some books and searched on the internet for papers and institutional information. I had great enthusiasm from service managers to initiate this type of intervention, and we decided to include it in our service at the *Clinica Psiquiatrica de S. José* of the Sisters Hospitallers of the Sacred Heart of Jesus, in Lisbon. In Portugal, by this time, there was almost an absence of research in this area, and very little was being done in practice. As a result, I was attracted to the psychoeducational paradigm, and the groups had greater emphasis on education. Of course, there were always moments for participants to share their concerns, and we gave advice on how to cope with patients' behaviours. Nevertheless, education was the dominant component. I was not happy with the kind of intervention we were delivering. It was too much top-down and therapists-led. On one occasion we decided to conduct a brief study, evaluating what relatives found important in the group. This led me to realise that the intervention should be more flexible and based on the needs of the relatives. Having in mind my cognitive-behavioural background, I was always a fan of structured interventions. Therefore, it was not the structure that was giving me concern. Instead, I had serious doubts whether the focus on education was really helping relatives.

In 2007, I had valuable help from a senior therapist. Professor Manuel Gonçalves Pereira was doing research in the field (the FAPS Project, a group intervention study with families of people with psychosis) and we conducted a few sessions together. This was a great opportunity to learn more about group dynamics, validation and positive reframing, that I was not used to employing in group settings.

Then I had the opportunity to attend the Behavioural Family Therapy course in the NOVA Medical School/ Faculdade de Ciências Médicas – *Universidade Nova de Lisboa* (NMS/ FCM – UNL), in Lisbon. In those days, this was almost the only opportunity to learn about family (psychoeducational) interventions for psychosis in Portugal, after the first training experiences that were run locally by Dr. Gráinne Fadden. Still, my curiosity around the process of family interventions for psychosis was never satisfied.

In the beginning of 2011, when I was starting my Doctorate, Professor Julian Leff and Professor Gonçalves Pereira gave me the opportunity to initiate a qualitative analysis of some historical materials that Professor Leff had kept for more than thirty years. These materials were the intervention records of the first clinical trial conducted by his team between 1977 and 1982 which proved to be highly effective.

By this time, I was also participating in a multicenter randomised clinical trial of a family psychoeducational intervention, in collaboration with the EDUCA group, from the *Instituto de Investigaciones Psiquiátricas de la Fundación Maria Josefa Recio*, in Spain. I was one of the therapists delivering the intervention in Portugal. Eventually, I participated in the two studies of this research group. The first, concerning carers of persons suffering from dementia, and the second relatives of persons suffering from psychosis. These studies were published in the meantime, and were an opportunity to increase my experience in the field.

After making the decision to adopt the analysis of the records of Professor Leff as my Doctoral research project, I started to read all I could obtain about this treatment approach.

In the end of 2011, I had a mission to London. This was a great opportunity to meet with Professor Leff. During those days, we had several conversations about the

intervention model and the work I should undertake. I also meet with other two therapists of the original intervention, Professors Elizabeth Kuipers and Ruth Berkowitz. These meetings were very fruitful. I came back to Portugal with the intervention records and a store of new knowledge.

Afterwards, we were intrigued to know what other qualitative research studies might have been published about the process of family interventions for psychosis. We decided to conduct a systematic literature review and we were surprised about the lack of research on this topic. We wrote an in-depth report of this work, that will be labelled in this thesis as Study 1. We submitted a manuscript reporting this review to Family Process, on October 2013, which has been revised and now waiting for a final decision. Part of Study 1 was also presented, and published in the book of abstracts, with the title “Searching for the active ingredients of effective family work in schizophrenia” in the “21st World Congress on Social Psychiatry”, that took place in Lisbon in July 2013.

By this time, we were also committed to define the methods for the qualitative analysis. I had several meetings with the supervisors and two qualitative research experts. Qualitative research was almost a novelty for me. I read a considerable number of papers describing qualitative research in other areas, and read benchmark books about the theme. The same happened with the NVivo® software (QSR International) for qualitative analysis. I accessed on-line courses and tutorials and had extended help from an NVivo® (QSR International) experienced user.

We had limited resources for this research project and we were in need of a research assistant to perform the independent coding in parallel with me. We applied for funds, but we were not successful. Fortunately, a junior psychologist, who had previous experience in qualitative process analysis, volunteered to collaborate.

The qualitative analysis was a demanding process. I was working full-time in my clinical and academic jobs, and a tremendous amount of work needed to be done. The transcripts had to be transferred to an electronic format and the qualitative analysis needed to be done continuously. In addition we were rewriting our systematic review to incorporate the changes suggested after peer-review.

By the summer of 2014, we had completed the qualitative analysis. I constructed databases and the exploration of the results started. The whole process was very exciting, as I started to see the answers for the questions that I had raised previously. The report writing of the qualitative analysis was the next step. In this thesis, it will be labelled as Study 2. This study will also be submitted to a peer-reviewed international journal and the preliminary results have already been presented, and published in the book of abstracts at the “XVI World Congress of the World Psychiatry Association” in Madrid in September 2014, with the title “Which are the key-components of family interventions for psychosis? A qualitative study”.

Having in mind the suggestions made by an external evaluators board, during a thesis preparation seminar that took place at the NMS/ FCM – UNL before the start of the coding process, we also had decided to conduct a third study, alongside the analytical approach used in Study 2. Study 3 was an inductive qualitative exploration of the same records using a narrative evaluation approach.

In this thesis, I report the work developed on my Doctoral research project comprising these three studies. The first chapter is a brief introduction, with a narrative and informal writing style, aiming to contextualize the reader with the development of the research of family interventions for psychosis. The focus of our research was on studies impacting on patients’ outcome, as this was also the main focus of the research over the years. Besides, this was also the outcome of the clinical trial we analysed in

this research project i.e. patients' course of the illness. We are aware of the relevance of other outcomes, such as family burden. We also acknowledge that these outcomes could be related. However, we considered that it would be beyond the scope of this thesis to focus on other research outcomes. One possible exception was the inclusion of studies in our systematic literature review that might also have family burden as an outcome. We were searching for information that was very difficult to retrieve, and therefore we decided not to be restrictive at this point.

Chapter 2 describes the systematic review (Study 1), aiming to identify studies about the process of FIP.

Chapter 3 is the main content of this thesis, reporting Study 2. This was a pioneering study and the overall results could be highly informative to define future directions in the research of FIP.

Chapter 4 was a complement to Study 2. It reports the work developed on Study 3 that comprised a description of our subjective perspective about what happened in the process of the intervention programme. This chapter also includes detailed information about the treatment approach, such as the basic assumptions and main strategies, that we found relevant to the purpose of our investigation.

The last chapter was intended to summarize our findings and to give brief and straightforward recommendations for the future.

As the reader may see, throughout this thesis we consistently use the term "family interventions for psychosis". Sometimes we use this expression when referring to interventions conducted only with patients with schizophrenia. We decided to generalise the term because there is strong evidence that the same interventions, which proved effective with schizophrenia, were equally effective with other psychoses, and because treatment groups tend to be heterogeneous including patients with

schizoaffective disorder. Moreover, the use of this comprehensive term would help the reader to be more focused on other essential contents.

The path along this research project was demanding but highly rewarding. Having the opportunity to answer to some of my initial questions when was introduced to family interventions was almost lyrical. Being supervised by Professor Gonçalves Pereira and Professor Julian Leff was a great experience. The opportunity I had to contact with the original therapists, during the mission to London, allowed me to feel the style and the environment related to what happened more than thirty years before, even when I was not born yet, and when history was being made, i.e. the development of a new treatment approach that could influence the life of so many people suffering from schizophrenia. The process of discovery along this research, and my enrichment with new research skills, were very fulfilling. But above all, I emphasise the personal experiences I got. I really believe that they contributed for my personal development as a researcher, as a therapist, and as a person overall.

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During my mission to London, I had the opportunity to meet with Professors Elizabeth Kuipers and Ruth Berkowitz, that kindly received me and shared thoughtful information. I am grateful to both as well.

I am also very grateful to my colleague psychologist Carla Nunes who volunteered herself to perform the independent coding of Study 2. It was such a

demanding task, and without her contribution, we will not be able to fulfil acceptable levels of validity and reliability in this study.

In the beginning of the project, I found myself as a rookie in qualitative research. The help of Professor Sónia Dias (*Instituto de Higiene e Medicina Tropical – Universidade Nova de Lisboa*) and my colleague PhD student Maria João Marques was decisive for a successful definition of the methods of Study 2. I am grateful to both.

Managing the NVivo® software (QSR International) for qualitative research was another challenge for me, since I had not any previous contact with the program before. I am thankful for the help of my colleague psychologist Catarina Morais, an experienced user of this software. Her advices were determinant for managing, coding and analysing data successfully.

As usual in this kind of work, the help of a biostatistician is crucial when analysing and interpreting data. I thank Professor Pedro Aguiar (*Escola Nacional de Saúde Pública – Universidade Nova de Lisboa*) all his dedication, and for wisely understanding what we needed with our analysis and giving thoughtful and very practical advices.

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CHAPTER 1

FAMILY INTERVENTIONS FOR PSYCHOSIS: THE RUBY JUBILEE

Introduction

While the development and the efficacy research of family interventions for psychosis (FIP) were remarkable and historical achievements, their clinical application and further research were marked both with successes and upheavals.

1.1 THE VERY BEGINNING

The reigning paradigm of FIP was driven by the discovery of the influence of relatives' expressed emotion (EE) in the course of schizophrenia by Brown, Monck, Carstairs and Wing (1962). EE was defined by five components: (1) criticism, that applies when relatives have the tendency to vocalize critical comments towards undesirable attitudes of the patients, namely those caused by the negative symptoms; (2) hostility, which comprises anger and irritation followed by critical comments rejecting the patient; (3) emotional overinvolvement, in which a relative, usually parents led by their feelings of guilt, show high doses of protectiveness, self-sacrifice, identification and emotionality, increasing dependence of the ill person on his caregiver; (4) warmth, reflected by kindness, concern, and empathy manifested by a relative while speaking about the patient; and (5) positive regard, comprising statements of appreciation, support and verbal or nonverbal positive reinforcement of patient's behaviour (Amaresha & Venkatasubramanian, 2012; Kuipers, Lam, & Leff, 2002). The first three components are negative, because they add stress to the environment, and the remaining two are positive because they are supportive and rewarding. EE is measured through the Camberwell Family Interview (CFI) by analysing how a relative talk about the patient

when interviewed alone. Brown et al. (1962) found different clinical evolutions between patients with schizophrenia living with high EE relatives and those living with low EE relatives. They found that one year after discharge from the hospital, 76% of the patients living with their high EE relatives had deteriorated their clinical state. By contrast, in the group of patients living with low EE relatives, only 22% had deteriorated. This was a noticeable finding grounding the rationale for tailoring interventions targeted to lower the “emotional temperature” of the family environment. After some replications of the influence of EE in the outcome of the illness (Brown, Birley, & Wing, 1972; Vaughn & Leff, 1976) researchers could not remain indifferent to this knowledge, and the first FIP approaches were born. Eventually two research groups made their progressions almost at the same time. Julian Leff and collaborators in London (Leff, Kuipers, Berkowitz, Eberlein-Vries, & Sturgeon, 1982) and Gerard Hogarty and collaborators in Pittsburgh (Anderson, Hogarty, & Reiss, 1980). These pioneer researchers had slightly different views about the role of the therapists in the intervention programme. As Hogarty stated, the aims of their intervention were achieved by “teaching the family appropriate management techniques for coping with schizophrenic symptomatology” (Anderson et al., 1980). This teaching role was beneath the development of the very well known concept of “family psychoeducation”. Over time FIP were depicted worldwide with this term, which inevitably called the attention to the education component of these interventions. On the other hand, the group led by Leff developed an approach where the relevance of education was lower. Their target was to regulate EE (i.e. over-involvement, hostility and criticism towards the patient) and to reduce face-to-face contact between the patients and their high EE carers. In a blend of settings of relatives

groups and single-family home sessions including the patient, participants received an array of pragmatic techniques, described later in a book (Kuipers et al., 2002).

The piloting and development of FIP was rapidly followed by efficacy research of these interventions. After the first successful attempt by Goldstein, Rodnick, Evans, May and Steinberg (1978), with a small follow-up at six months, Julian Leff and collaborators demonstrated, with a powerful controlled trial¹, the large effect of FIP on relapse prevention. They observed a reduction in relapse rates from 50%, in the control group, to 8% in the treatment group, over nine months (Leff et al., 1982). With a follow-up of two years the results remained notable with a reduction in relapse rates from 78% (controls) to 14% (experimental) (Leff, Kuipers, Berkowitz, & Sturgeon, 1985). These findings paved the road to a growth in research about the efficacy of FIP and the development of new treatment approaches.

1.2 THE DEVELOPMENT OF NEW EFFECTIVE APPROACHES

The work by Ian Falloon and collaborators was one of the most important contributions to give a step-by-step manualized structure to FIP (Falloon, Boyd, & McGill, 1984). They developed the Behavioural Family Therapy (BFT), a single family intervention, delivered at home or at the service. After engagement, education and relapse prevention oriented techniques, the family including the patient, receive a package of techniques using the behavioural training approach. This training programme aims to improve problem-solving and communication skills within the

¹ This clinical trial will be explored in depth in Chapters 3 and 4.

family (e.g. expressing positive feelings; making positive requests; expressing unpleasant feelings; active listening; and problem-solving). BFT requires great commitment by the family, systematic monitoring and homework assignments. There was a large effect on decreasing relapse rates from 44% to 6% at nine months (Falloon et al., 1982) and from 83% to 11% over two years (Falloon et al., 1985).

Years later another FIP approach was born. (McFarlane, 1991) developed the Multifamily Group Therapy, a new model integrating psychoeducation workshops only for relatives and psychoeducational groups for relatives and patients. The programme starts with at least three engagement sessions individually with patients and relatives. Afterwards relatives attend to a psychoeducational group workshop, followed by several multifamily groups including the patients. The themes of the multifamily groups are focused on education about the illness and problem-solving, with a socializing component (McFarlane, 2002). This approach eventually became very popular and was a lever for expanding FIP particularly in the USA (McFarlane et al., 1993). It also proved its efficacy, showing a decreasing of relapse rates to 25% over two years (McFarlane, Lukens, et al., 1995) and 50% over four years (McFarlane, Link, Dushay, Marchal, & Crilly, 1995).

1.3 THE APOGEE OF FIP: THEIR INCLUSION ON THE MOST IMPORTANT TREATMENT GUIDELINES

The efficacy studies of FIP were remarkable findings and turned the attention of the scientific community. After the first replications of the original studies it was very easy to review in the literature studies demonstrating no effect of FIP because they were

very few (McFarlane, Dixon, Lukens, & Lucksted, 2003). The existence of a psychosocial treatment showing consistently a robust effect on the outcome of schizophrenia was an important asset to the recovery of this condition. Inevitably, the next step on the timeline of FIP was the support of the individual findings by thoughtful reviews and meta-analysis.

In this scope, Lam (1991) made the first contribution by reviewing the state of the art of FIP. The author reviewed the outcome of the most relevant studies confirming in aggregate the effect of FIP on relapse prevention. The author also found that despite that a few education sessions could have some positive impact in the family, they are unsuccessful to prevent long-term relapses.

Years later, Goldstein and Miklowitz (1995) conducted a review about studies comparing FIP with treatment as usual, and confirmed the robust effect of FIP in clinical outcome. They also found that not every type of FIP could reach the maximum expected outcome. They questioned the efficacy by type and format of intervention, and found that few sessions of family education, even if they include the patient, are insufficient to promote long-term changes on the course of the illness. This evidence was consistent with the idea advanced by Lam (1991). Goldstein and Miklowitz (1995) also found that regular, intensive home-based sessions with individual families do not take great advantage as compared with group formats.

In the same year, Dixon and Lehman (1995) published the first review based on a comprehensive search of the relevant literature. They reinforced previous contributions, finding substantial evidence demonstrating the reduction in relapse rates by FIP. They also found that FIP improved patients' functioning and family well-being. Moreover, they stated that group interventions may take some advantage over single-

family interventions if they include the patient and if therapists had take at least three individual engagement sessions with the patients and the relatives. This advantage was better demonstrated on interventions with high EE relatives.

The review of Dixon and Lehman (1995) impelled FIP to be included in the Schizophrenia Patient Outcome Research Team (PORT) treatment recommendations (Lehman & Steinwachs, 1998). This document endorsed three recommendations for FIP: “(1) patients who have ongoing contact with their families should be offered a family psychosocial intervention that spans at least nine months and provides a combination of education about illness, family support, crisis intervention, and problem-solving skills training. Such interventions should also be offered to nonfamily caregivers; (2) family interventions should not be restricted to patients whose families are identified as having high levels of "expressed emotion" (criticism, hostility, overinvolvement); (3) family therapies based on the premise that family dysfunction is the etiology of the patient's schizophrenic disorder should not be used.”

By this time, FIP had achieved high relevance as an effective treatment option for schizophrenia, especially in the USA, and their dissemination started abroad.

In 2000, Dixon, Adams and Lucksted (2000) updated the work from Dixon and Lehman (1995). They included in this updated review, studies with participants from other cultural groups; studies with relatives of recent-onset patients; and studies comparing FIP with sophisticated individual therapy models. This review also included a wider range of outcomes, comparing different strategies and studies with extended follow-up. The results remained convincing and some additional recommendations were stated, namely the need to adapt culturally the programme. The authors also found that therapists must be sensible with low EE relatives, giving them emotional support,

instead of driving these relatives to interventions that they do not need, such as communication training.

Dixon et al. (2001) made another seminal review, reinforcing previous evidence. In this paper the authors confirmed the idea advanced by Lam (1991) and Goldstein and Miklowitz (1995), finding further evidence that education alone was ineffective in preventing relapses. This review was now addressing other mental disorders, such as major depression, bipolar disorder, anorexia, obsessive-compulsive disorder and borderline personality disorder. It also highlighted the need to conduct further research to develop programmes tailored to individual family characteristics, such as procedures to enhance engagement and access, and the need to develop different approaches for different levels of EE.

In 2000, Julian Leff made a comprehensive review about the practical application of FIP (Leff, 2000). The author reviewed three levels of FIP research i.e. studies of efficacy, effectiveness and efficiency. This paper confirmed the effectiveness of FIP by reviewing more than a dozen of clinical trials. The author made straight recommendations on the efficiency of FIP stating that relatives groups are efficient in saving staff time, and that multiple family groups may be more efficacious than single-family sessions. However, as many relatives refuse to attend a group, in these cases it is recommended to include a few single-family home sessions to promote engagement.

Despite there had been so many reviews, the first comprehensive meta-analysis of FIP was only later conducted by Pitschel-Walz, Leucht, Bauml, Kissling, & Engel (2001). They reviewed 25 studies concluding that FIP reduce relapse rates by 20%. This effect was particularly strong if programmes took more than three months.

McFarlane et al. (2003) made another seminal review by highlighting the efficacy of various FIP models across more than 30 clinical trials and by integrating all previous contributions with conceptual descriptions and recommendations about the implementation of FIP.

As a corollary of such level of evidence, in 2003, FIP were included in the NICE guidelines as effective treatment options for schizophrenia and maintain their position until nowadays (National Institute for Health and Clinical Excellence, 2014).

The Cochrane Collaboration had also made their evaluation of the efficacy of FIP by including a series of meta-analysis quantifying the effect of FIP (Pharoah, Mari, Rathbone, & Wong, 2006, 2010; Pharoah, Mari, & Streiner, 2000; Pharoah, Rathbone, Mari, & Streiner, 2003). The updated analysis confirmed that FIP may: (1) decrease relapse rates ($n = 2981$, 32 RCTs, RR 0.55 CI 0.5 to 0.6, NNT 7 CI 6 to 8); (2) reduce hospital admissions ($n = 481$, 8 RCTs, RR 0.78 CI 0.6 to 1.0, NNT 8 CI 6 to 13); and (3) improve compliance with medication ($n = 695$, 10 RCTs, RR 0.60 CI 0.5 to 0.7, NNT 6 CI 5 to 9). FIP also seem to improve general social functioning and reduce the levels of expressed emotion within the family (Pharoah et al., 2010).

Throughout the last 25 years at least 12 reviews showed consistently a considerable effect of FIP on relapse prevention. This is an outstanding achievement placing a psychosocial treatment as a shield on the course of the illness. Besides patients' outcomes FIP also proved their worth in reducing caregivers' burden (Magliano, Fiorillo, Malangone, De Rosa, & Maj, 2006). Today there is no doubt to consider as a best practice the delivering of family interventions alongside standard treatment in psychosis.

1.4 THE UPHEAVALS OF THE IMPLEMENTATION OF FIP

Despite the unequivocal efficacy of FIP, their implementation has been strikingly difficult. Fortunately there were some exceptions. In Europe, the Meriden West Midlands Family Programme in the UK was one of the best examples of successful dissemination of FIP (Fadden, 2006; Fadden, 2011). The Psychoeducating project was yet another important initiative trying to explore implementations issues in six countries i.e. Italy, Germany, Greece, Portugal, Spain and UK (Gonçalves-Pereira, Xavier, & Fadden, 2007; Magliano et al., 2005). In the USA, The New York Family Support Demonstration Project was also an example of successful implementation (McFarlane et al., 1993). However, surveys indicated an underuse of FIP (Cohen et al., 2008). Several barriers arise when considering the practical application of FIP in routine care. This effect was observed in the USA (McFarlane et al., 1993), in the UK and in Australia (Leff, 2000). A comprehensive survey in two national health systems in the USA revealed that less than 7% of families receive FIP (Dixon et al., 1999). Having in mind that schizophrenia is one of the most disabling diseases (World Health Organization, 2001) it is odd that a cost-effective treatment has not been used. The question seems to be related to the degree of commitment of practitioners and managers of the healthcare services (Leff, 2000). For a successful implementation of FIP two barriers must be overcome: (1) the excessive case load of clinicians; and (2) the lack of time to prepare and conduct the intervention sessions. It is crucial to advocate with service managers so that they feel attracted by FIP (Leff, 2000). Like medications have a strong marketing resource for their implementation a lever for better implementation of FIP could be the development of a strong campaign about the efficiency of FIP. This

may also overcome myths about the costs and other philosophical and sceptical issues involving implementation (Hogarty, 2003). Additionally, efforts must be made to overcome participants' barriers. The sense of stigma and burden may be the most compelling reasons for families to refuse or drop-out of FIP. An effective solution to deal with this issue is to involve families in collaboration with professionals in the implementation of FIP programmes. This was demonstrated by one of the most popular families' organization, the National Alliance for the Mentally Ill (NAMI) in the USA. Moreover, participants' barriers may also be overcome by addressing a few single-family sessions to facilitate engagement and avoid refusals and drop-outs (Leff, 2000).

1.5 THE FALLACY OF THE EDUCATION COMPONENT: THE HALO EFFECT AND THE MYTH OF ORPHEUS AND EURYDICE

It was told by some authors that, when the effect of EE on the course of the illness was found, relatives tended to refuse this concept. This was especially found in the USA. Efforts were made to demystify the influence of relatives on the aetiology of the illness and to diminish their willingness on the development of high EE. Authors explicitly argued that EE was a consequence of the illness rather than a cause for the illness (Leff et al., 1982; McFarlane & Cook, 2007). However, this information seemed difficult to accept at that time. Eventually, families did not reject the idea that high EE could be related to the lack of help they received, namely the lack of information they were receiving from the professionals. An acknowledged solution to overcome the resistance of burdened families to accept the construct of EE, and consequently to accept a treatment programme, was to highlight the need for information that families

felt. The term “psychoeducation” was applied to this type of family interventions. The teaching role of the therapists was highlighted, and as consequence families would expect information giving as the main “job” from the professionals when delivering FIP (Anderson et al., 1980). As a result the education component acquired a greater emphasis on FIP. Education became the front view of FIP, relegating the other components to the second row. We can see this tendency in treatment models such as the Multifamily Group Therapy (McFarlane, 2002), the PORT recommendations (Dixon et al., 2010), and even in the updated NICE Guidelines (NICE, 2014). When considering the practice of FIP, all these important references enunciate at first glance the education component. This pathway invariably took place without the empirical knowledge about the process of FIP and without the evidence about the key-elements or active ingredients of FIP. A very attractive idea about FIP (i.e. an intervention targeted to fulfil the gap of information felt by families) suffered the halo effect. FIP started to be known by the education component. However, education was only one part of the intervention. Should it be the primary one? For example, (Vaughan et al., 1992) did not found any impact of their educational intervention on patients’ relapses. It appeared that providing relatives with information about the illness increases knowledge and may improve attitudes, but did not yield the behavioural changes required to impact on the prognosis of the illness. As mentioned above, Lam (1991) was the first to advocate based on a comprehensive review that there was no evidence to consider education the primary component of FIP. The author argued that more research was needed to understand which are the active ingredients of FIP. Others reinforced the idea e.g. (Dixon et al., 2001).

The concerns about the key-elements of FIP became increasingly stronger in the end of the 1990's after the first generation of efficacy studies. The fact that different FIP approaches all led to positive outcomes was an intriguing question. For example the Multifamily Group Therapy (McFarlane, 2002) was based on the psychoeducation paradigm, with a supposed strong component of education resembling the approach from Anderson et al. (1980). By contrast, the models of Leff and Falloon placed greater relevance on helping families to cope better with patients' behaviour (Gonçalves-Pereira, Xavier, Neves, Barahona Correa, & Fadden, 2006). The World Fellowship for Schizophrenia and Allied Disorders launched an initiative aiming to promote a consensus of the most relevant authors: Falloon, Leff and McFarlane. This meeting ended in the definition of two goals and fifteen principles underlying family interventions for schizophrenia (World Fellowship for Schizophrenia and Allied Disorders, 1997). This document endorses major recommendations, particularly on the environment and context of the interventions, the type and quality of the relationship to develop with family members, and the major themes to address in the sessions. These themes included family expectations, strengths and difficulties, conflict, feelings of loss, encouragement of clear communication, problem-solving and the expansion of social support networks. Undoubtedly the consensus was a step in promoting a broader knowledge about the components of FIP. Unfortunately this was not enough to understand the process of FIP.

More than 20 years after the question unveiled by Lam (1991) we still do not understand exactly the process of FIP (Cohen et al., 2008; Dixon et al., 2001; Glynn, 2012; Leff, 2000; McFarlane et al., 2003). This fact resembles the ancient Greek myth of Orpheus and Eurydice. Like Orpheus carried in his back the beautiful Eurydice into

the upper world and could not look into her face otherwise she would be lost forever, authors and clinicians carried in their arms a stunning intervention and could not see its essence.

By acknowledging the current state of the art about FIP, we found strong reasons advocating that one should definitely attempt to understand the process of FIP (Cohen et al., 2008; Dixon et al., 2001; Lam, 1991; Leff, 2000; McFarlane et al., 2003). In the following chapters we will describe our research on searching for the key-elements of FIP. This information will be determinant to draw conclusions about the process of these interventions.

CHAPTER 2

WHAT DO WE KNOW ABOUT THE PROCESS OF FAMILY INTERVENTIONS FOR PSYCHOSIS? A SYSTEMATIC REVIEW

Study 1

A revised version of this chapter was submitted to Family Process.

Grácio, J; Gonçalves-Pereira, M; Leff, J. What do we know about family interventions for psychosis at the process level? A systematic review. *Family Process* (submitted)

2.1 BACKGROUND

Psychotic-spectrum disorders are complex biopsychosocial conditions and family issues are important determinants of prognosis (Butzlaff & Hooley, 1998). The effectiveness of FIP in relapse prevention and family wellbeing is widely recognized, prompting their inclusion as effective treatment options in the PORT recommendations and NICE guidelines (Dixon et al., 2010; McFarlane et al., 2003; National Institute for Health and Care Excellence, 2009).

The most remarkable demonstrations of the efficacy of FIP were at their very beginning (e.g. Anderson et al., 1980; Falloon et al., 1985; Leff et al., 1982; Leff et al., 1985) and since these first studies the majority of FIP approaches have been designated under the label of “family psychoeducation” (Eack, Schooler, & Ganguli, 2007; Jewell, Downing, & McFarlane, 2009). However education is only one component of a complex intervention.

The main authors of FIP developed treatment manuals and books based on their practice, containing detailed descriptions of the elements, structure and some process issues, e.g. Behavioural Family Therapy (Falloon et al., 1984), Multifamily Group Therapy (McFarlane, 2002), and the combined method of individual family sessions and relatives groups (Kuipers et al., 2002). Despite sharing commonalities, these treatment approaches had clear methodological differences but all led to similar positive outcomes. The debate questioning the major components of FIP was opened. McFarlane (1991) suggested core practical ingredients based on the aims of the intervention (i.e. establishing an empathic collaboration with family members; education about the illness; problem-solving; development of coping skills; communication skills training;

and expanding social support networks). Liberman and Liberman (2003) revised these components, framing them in a broad process of recovery recycled over time accordingly to the needs of the families. Later on, Kuipers (2006) advocated a focus on family interaction, arguing that the crucial ingredient of FIP is to replace stress, anxiety and criticism with more tolerant and effective reappraisals, and a problem-solving attitude.

On this subject, the World Fellowship for Schizophrenia and Allied Disorders had launched a seminal initiative, by promoting a consensus of practitioners: Falloon, Leff and McFarlane. This ended in the definition of the principles underlying the family work for schizophrenia (WFSAD, 1997).

Despite the great value of all these contributions, so far, no one has investigated the individual contribution of each key-element in a research project and it remains unclear how and why FIP actually work (Cohen et al., 2008; Dixon et al., 2001; Lam, 1991; Leff, 2000; McFarlane et al., 2003). As Cohen et al. (2008) stated “we have limited knowledge of the critical elements in the interventions. More data on the mediators, or critical elements, would increase the likelihood of successful implementation of family psychoeducation.” An initial limited attempt at this was the study of the family sessions in comparison with a relatives’ group that showed that when relatives attended the group their patients had an identical outcome to those patients involved in the family intervention (Leff et al., 1989). A massive investment of time and effort would be needed to conduct a series of trials in which one or other component of a specific intervention package would be omitted (Leff, 2000). We are considering complex interventions and attempting to isolate elements that interact with each other, either to enhance their effectiveness or to weaken it. The skill, experience

and empathy of the therapists are confounding factors increasing the difficulty of this task. Nevertheless, we should attempt some clarification of these difficult issues by exploring empirical clues underlying the efficacy of FIP. It might be possible to isolate key-elements crucial to the process by examining studies that report on variables of the process.

We are aware of our use of a variety of different terms for the same purpose: “active ingredients”, “key-elements”, “variables” and “components”. We are not unique in this usage as others have been equally inconsistent in their terminology (Cohen et al., 2008; Dixon et al., 2001; Kuipers, 2006; Lam, 1991; Leff, 2000; McFarlane et al., 2003). Throughout this paper, those terms will be used interchangeably for addressing complex interactions that involve discrete interventions, participants’ characteristics and the qualities of the therapist. We do not expect to find a definite solution to these problems, but consider it worth initiating this endeavour.

2.2 AIMS

This paper reports a review of studies addressing the process of FIP. Our aim was to identify process analyses of the interventions, which could allow the identification of key-elements and drawing of conclusions about the relationships between process and effective outcomes.

2.3 METHODS

2.3.1 Data Sources

We conducted a literature review on the subject of variables related to the process of FIP, including studies up to 31 December 2013. Searches were performed accessing the following medical, psychological and educational databases: PubMed/MEDLINE; Web of Science and EBSCO Host included databases (Academic Search Complete; Education Research Complete; Education Source; ERIC; and PsycINFO). Combinations of the following key-words were used with truncations: schizophrenia; psychosis; family; psychoeducation; process; elements; active ingredients; and qualitative study. Only papers in English and Portuguese were included, otherwise no other limits were imposed. An example of a search strategy is presented in the Table 1. We also searched using Google and Google Scholar on the internet, and manually by checking the reference lists of relevant papers.

2.3.2 Eligibility

We searched for any empirical studies presenting data that could allow us to draw conclusions about the process of FIP. Our primary focus was on qualitative studies, because they enable a comprehensive exploration of the interventions at the process-level, for example therapeutic alliance, group dynamics, themes, core techniques, mediating variables and mechanisms of change. However, we chose not to be restrictive on the basis of study design, because of the reported difficulties in retrieving qualitative information under the label of “qualitative research” (Higgins &

Green, 2011), and because it is also possible to find process related information in papers using quantitative data.

Table 1
Example of a search strategy using PubMed/ MEDLINE

Search	Query	Results
#23	Search ((#20) AND #21) AND #22	20
#22	Search (((#15) OR #16) OR #17) OR #18) AND #19	17378
#21	Search (((((((#5) OR #6) OR #7) OR #8) OR #9) OR #10) OR #11) OR #12) OR #13) OR #14	238944
#20	Search ((#1) OR #2) OR #3) OR #4	222291
#19	Search component* [TW]	632321
#18	Search active AND ingredient* [TW]	7678
#17	Search key AND element* [TW]	24458
#16	Search content AND analys* [TW]	178513
#15	Search Qualitative Research [MH]	13072
#14	Search careg* AND intervention* [TW]	7167
#13	Search careg* AND psychoeducat* [TW]	236
#12	Search careg* AND educat* [TW]	7482
#11	Search careg* AND group*	6918
#10	Search relative* AND group* [TW]	179097
#9	Search famil* AND educat* [TW]	21731
#8	Search famil* AND work [TW]	12512
#7	Search famil* AND intervention* [TW]	15052
#6	Search famil* AND psychoeducat* [TW]	306
#5	Search Family Therapy [MH]	7232
#4	Search schizophreni* [TW]	103275
#3	Search psychos* [TW]	114969
#2	Search (severe OR serious) AND mental* AND ill* [TW]	9619
#1	Search Schizophrenia and Disorders with Psychotic Features [MH]	107337

Inclusion criteria

We included studies of participants who were relatives of patients with a diagnosis of psychosis (mainly schizophrenia and schizoaffective disorder) and that

examined interventions with the underlying paradigm of psychoeducational family work.

Exclusion criteria

We excluded papers only providing conceptual descriptions or studying the effectiveness of a particular approach, and comparisons of different treatment models without an evaluation of individual elements of the process (i.e. more than one treatment component in comparison and evaluations of intervention modalities such as length of the programme, single versus group interventions).

We also excluded studies specifically addressing mutual support groups for relatives, which are not run by a therapist, and studies of Systemic Family Therapy.

2.3.3 Screening and Assessment of Eligibility

We followed the PRISMA Statement on the procedure for systematic reviews (Moher, Liberati, Tetzlaff, Altman, & The PRISMA Group, 2009). After discussions with the supervisors, we reached an agreement on the assessment of eligibility by screening a sample of searched papers. The initial assessment was carried out by the author. The titles and abstracts of search references were screened according to the inclusion criteria and a list of papers with potential for eligibility was generated. Further screening was undertaken by the author together with one supervisor (MG-P) and then discussed with the other supervisor (JL). Full-text articles were reviewed and a final decision was made on their inclusion in this study.

2.3.4 Data Extraction and Synthesis

Data were highlighted from full-text articles and summarized. Information related to sample, study design, type of intervention, methods and major findings was retrieved. Any other relevant empirical information related to the process was extracted.

Qualitative Synthesis

We performed a content analysis of the major findings of each paper. Categories were based on the data presented in the papers through recognition of the elements that were identified as being major ingredients in the interventions. A qualitative rating system was produced (*+important*; *++ prominent*; and *+++ highly prominent*), scoring our judgement of the level of prominence of the elements identified as being major ingredients of the interventions. These tasks were accomplished by the author and one supervisor (MG-P) reaching a consensus on the ratings.

2.4 RESULTS

A total of 729 articles were retrieved from the electronic databases and four papers were identified through other sources. Seventy duplicates were deleted and 663 references were screened according to inclusion criteria. Thirty-eight full-text articles were assessed for eligibility. Sixteen studies were then excluded, due to no presentation of specific empirical data on process-related variables and therefore with no potential to isolate treatment elements. After this final screening, 22 relevant papers were found and formed the basis of this review. In Figure 1, the flow of information through the different phases of this review is presented.

Figure 1

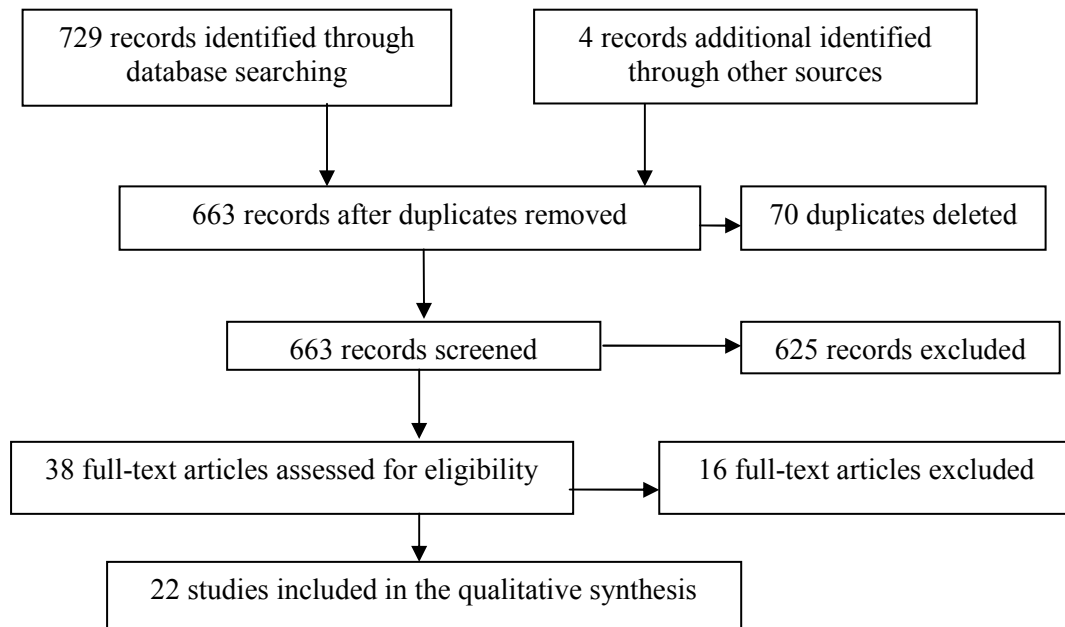


Figure 1. PRISMA Flow of information through the different phases of the systematic review.

To structure the analysis and aid comparisons, studies were grouped into four categories (1) studies comprehensively examining the process of an intervention; (2) participants' opinions about the intervention received; (3) comparative studies individualizing process-related variables; and (4) exploration of mediating variables related to FIP outcome. Table 2 provides an overview of each paper we analyzed.

Table 2
Summary of Studies Included in the Qualitative Synthesis

Authors and year	Country	Study design	Number of participants (number of women)	Age: mean; range (years)	Intervention			Methods and measures	Major findings
					Number of sessions	Duration (weeks)	Treatment (setting)		
<i>Studies comprehensively examining the process of an intervention</i>									
Bloch et al. (1995)	Australia	QUAL (of a CS)	30 relatives: 15 mothers; 4 fathers; 3 daughters; 4 sisters; and 4 spouses	Not reported	6	6	Individual counselling program for caregivers based on education and coping skills training (home based)	Examination of the process regarding themes, therapeutic interventions and caveats for counsellors	Wide range of themes concerning personal, coping and family/ social aspects of the caregiving experience; Major themes identified: sharing personal narratives; Major interventions identified: support and validation; Overall conclusions: Family interventions should be needs focused and therapists must assume a great array of roles in the program

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Studies on participants' opinions about the intervention received

Barrio and Yamada (2010)	USA	QUAL (of a CS)	QUAL: 52 relatives of 26 patients; CS: 118 relatives of 59 (51) patients	Not reported	16	Not reported	Not reported	Relatives groups; Themes: engagement, education and integration of cultural aspects with the illness and carer role (service based)	Family burden/wellbeing and patients' symptoms	Post study focus groups with the participants	Relatives reported positive changes in knowledge, attitudes and practices towards patients by reframing the views about the illness; Relatives valued the atmosphere of the group by being needs focused, culturally sensitive, supportive and therapeutic
Budd and Hughes (1997a)	UK	QUAL	20 (16) relatives of 20 patients: 15 (12) parents; 3 wives; and 1 sister	Relatives: 50; 28-65; Patients: 29; 18-54	Not reported	Not reported	Not reported	Single-family sessions including the patient, containing an educational package followed by problem-solving and communication skills training (home based)	Not clearly reported	Semi-structured interviews; Participants were asked about what they found helpful and unhelpful in the intervention; Data were coded into categories and reanalysed using a rating system	Nonspecific positive impact of emotional support, backup and reassurance were more commonly reported as helpful than behaviour change and skills acquisition
Budd and Hughes (1997b)	UK	QUAL	20 (16) relatives of 20 patients: 15 (12) parents; 3 wives; and 1 sister	Relatives: 50; 28-65; Patients: 29; 18-54	4-5	Not reported	Not reported	Single-family sessions including the patient, containing an educational package about symptoms, aetiology, medication and services (home based)	Not clearly reported	Semi-structured interviews; Participants were asked about what they found helpful and unhelpful in the intervention; Data were coded into categories and reanalysed using a rating system	The elements most cited as helpful were education and knowledge acquisition; Relatives also significantly cited that the program helped to reattribute problem behaviour to illness

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Buksiti et al. (2006)	Denmark	Descriptive, cross sectional	35 relatives of 26 (10) first-episode patients	Relatives: not reported; Patients: 19-34	8	16	Short-term family group sessions based on psychoeducational and psychodynamic principles (service based)	Not clearly reported	Relative's survey; Self-reporting questionnaires comprising four item groups: education; cooperation with services; opportunity for sharing; and dealing with shame and guilt	Relatives mostly appreciated the gain of knowledge about schizophrenia and the possibility of sharing thoughts and feelings with others; Group leaders attitude and the opportunity to listening to other relatives were considered important factors
Cabral and Chaves (2010)	Brazil	Descriptive, cross sectional	65 (31) caregivers (19 mothers) of 46 first-episode patients	Not reported	Not reported	Not reported (weekly sessions)	Multifamily Group Therapy (service based)	Family burden/ wellbeing and patients' symptoms	Caregiver's satisfaction self-reporting questionnaire	Non-specific aspects of the intervention were quoted as the most useful part of the programme
James et al. (2006)	UK	QUAL	7 (4) relatives from 3 families and 7 (4) therapists	Relatives: 25-85; Therapists: 26-65	One family had 12 sessions and others had extended involvement	Not reported	Behavioural Family Therapy (home based)	Family burden/ wellbeing and patients' symptoms	Semi-structured interviews were analysed based on grounded theory approach, focusing on the engagement process	Therapists' qualities such as humanity and being a reflective practitioner appear crucial in the engagement process
Levy-Frank et al. (2012)	Israel	QUAL (of a CS)	93 (73) parents of 93 (29) patients	Relatives: 57.4 (Group A) and 58.7 (Group B); Patients: 35 (Group A) and 36.6 (Group B)	15	Not reported	Group A: Multifamily Group Therapy; Group B: Therapeutic alliance focused therapy (service based)	Family burden/ wellbeing and patients' symptoms	Semi-structured interviews using The Narrative Evaluation of Intervention Interview; Data were coded and analysed using the grounded theory approach	Empathy, positive regard, guidance and advising were seen as most useful strategies in both groups; Only education and group regulation had different weights, each one being prominent in group A and B respectively

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Mannion (1997)	USA	QUAL (of a CS)	19 relatives (13 parents – 9 mothers, 1 sibling, 2 children, 2 friends). They were past members of group psychoeducational workshops	Not reported	4	4	Group consultation (therapists individualized answers to participants' questions and problem-solving techniques) (service based)	Not clearly reported	Process evaluation questionnaire about reactions to the new group format and its usefulness	Participants valued the feeling of support, individualized information-giving, the opportunity of sharing and listening to others, and problem-solving directed to their own needs
Riley et al. (2011)	UK	QUAL	12 relatives First-episode patients	Not reported	8	Not reported	Relatives' education group with a "catch up" moment where relatives expressed any issues occurring to them	Family burden/wellbeing	Focus group to evaluate what happened in the intervention; Thematic analysis of the transcripts using computer software; Common themes were identified through independent coding and correlational analysis of data	The most important components of the intervention were: (1) the emotional impacts – loss, grief, guilt, shock, acceptance; (2) isolation and stigma; (3) the caring role and how this affected relationships; (4) discussions about the design of the group; and (5) the wider impacts of the participation (education and the importance of sharing own experiences)
Stanbridge et al. (2003)	UK	QUAL and descriptive, cross sectional	21 relatives (11 mothers, 6 fathers, 2 wives, 1 sibling, 1 aunt); and 4 (0) patients	Not reported	10 families attended 1 to 18 sessions (average 6.5) and 5 families attended 5 to 25 sessions (average 16.4)	Not reported	Single-family cognitive-behaviour therapy plus family therapy with a systemic perspective (home and service based)	Not clearly reported	Semi-structured interviews subjected to thematic content analysis; A satisfaction rating scale was quoted	Relatives valued: the therapeutic alliance; the opportunity for open discussion; the development of new perspectives; problem-solving; and the possibility to work closer with services

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Sundquist (1999)	USA	QUAL	1 daughter; 1 patient (mother)	Patient: 65	Extended involvement (more than 8 years)	From one session every 6 weeks to 3 meetings per year	Single-family sessions and group psychoeducational workshops (service based)	Not clearly reported	Relative's first person account, describing her opinion and narrative about the usefulness and process of the intervention	The relative reported increased skills on how to respond effectively to patient symptoms and how identify stress producing situations and the different stages of the illness
Comparative studies individualizing process-related variables										
Brichwood et al. (1992)	UK	CS	94 relatives of 82 (20) patients	Relatives: not reported; Patients: 29,4	4	Groups A and C: not reported; group B: 4 weeks	Information giving and education through three different methods; Group A: group educational sessions involving semi-structured seminars; Group B: delivering of postal information containing four booklets with therapists; Group C: videos containing four information sections, plus discussion with therapists;	Not clearly reported	Comparison of three groups controlling methods for delivering education; Relatives were assessed with the following questionnaires: Knowledge Questionnaire; Symptom Rating Test; The Family Distress Scale; The Symptom Related Behaviour Disturbance Scale; The Social Functioning Scale	Greater knowledge acquisition when information is delivered in a group, but these differences were not maintained at six-month follow-up; Information giving led to considerable gains in knowledge, increased optimism concerning the family's role in treatment, and reductions in relatives' stress; The delivery of information, rather than the mode of delivery, is the crucial element in the intervention. However, the additional contextual factors operating in a group may be determinant for reaching other therapeutic goals

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Kane et al. (1990)	USA	CS	49 (32) relatives (27 mothers, 14 fathers, 4 sisters, 3 brothers, 1 aunt) comprising 37 families	Relatives: 49; 27-76; Patients: 26	4	4	Relatives groups; One group received a psychoeducational intervention based on interactive instructional activities; The other group had support group intervention with non-structured discussions (service based)	Family burden/wellbeing	Assessment before and after the group: Relatives were assessed on knowledge acquisition, perceived social support, distress and inability to cope with patients' behaviour	The psychoeducational group had a greater effect on satisfaction with the intervention, and decreasing depression; Support groups may not be compatible with a short time frame
Levy-Frank et al. (2011)	Israel	CS	93 (73) parents of 93 (29) patients	Relatives: 57.4, 41-73; Patients: 35, 17-49	15	Not reported	Group A: Multifamily Group Therapy; Group B: Therapeutic alliance focused therapy (service based)	Family burden/wellbeing and patients' symptoms	Process-outcome model to compare the effectiveness of the two interventions and to evaluate how they achieved their outcomes; Measures: parents' family burden, parents' perception of patients' quality of life and psychiatric symptoms	No differences between groups; Both interventions showed, at the post-treatment phase, less family burden, and improved quality of life and less psychiatric symptoms of the patients
Tarrier et al. (1988)	UK	CS	83 families of 83 (54) patients	Relatives: 53; Patients: 35.3	13	36	Four different treatment strategies: two groups received behavioural interventions with different techniques, enactive and symbolic; one group education only and the final group treatment as usual	Family burden/wellbeing and patients' symptoms	Comparison between groups assessing for differences in relapse rates and levels of EE between relatives at admission, four months and nine months	Relapse rates were lower for patients whose families were in the two behavioural intervention groups compared with education only; Education alone program is ineffective in reducing relapses; Changes from high to low EE occurred in all groups but were more pronounced in behavioural intervention groups

Studies on the exploration of mediating variables related to FIP outcome

Barrowclough and Hooley (2003)	UK	Review	Not applicable	Not applicable	Not applicable	Not applicable	Not applicable	Not applicable	Not applicable	Review of all published studies on attributions of high and low EE in relatives and carers	Relatives' attributions about patients' behaviours may mediate EE; Interventions that use reattribution techniques that validate relatives' perspectives may reduce criticism and hostility
Bentsen et al. (1997)	Norway	Descriptive, partly cross-sectional and partly longitudinal (stability of locus of control)	70 relatives (35 mothers, 29 fathers, 3 spouse and 3 siblings, 47 (17) patients)	Relatives: 56.5; 26-82; Patients: 28.5; 18-39	Not applicable	Not applicable	Not applicable	Not applicable	Not applicable	Examination of locus of control beliefs as determinants of EE.; Relatives were assessed with the CFI and Levenson's Internality, Powerful Others and Chance Scales; Data explored through confirmatory regression analyses	Locus of control beliefs may be determinants of overinvolvement and criticism
Bentsen et al. (1998a)	Norway	Descriptive, cross sectional	72 relatives (37 mothers, 29 fathers, 6 spouse and siblings) of 47 patients	Relatives: 56.7; 28-82; Patients: 28.5	Not applicable	Not applicable	Not applicable	Not applicable	Not applicable	Relatives' EE was assessed with the CFI; Demographic and clinical data were used as predictor variables in confirmatory regression analyses	Interventions to reduce EE should modify relatives' unrealistic expectations about employment of the patients

CHAPTER 2 - WHAT DO WE KNOW ABOUT THE PROCESS OF FAMILY INTERVENTIONS FOR PSYCHOSIS? A SYSTEMATIC REVIEW

Bentsen et al. (1998b)	Norway	Descriptive, cross sectional	69 relatives (34 mothers, 29 fathers, 3 spouse and 3 siblings) of 46 (17) patients	Relatives: 56.5; 26-82; Patients: 28.7	Not applicable	Not applicable	Not applicable	Examination of guilt as determinant of EE; Relatives were assessed with the CFI and guilt with the Revised Mosher Guilt Inventory; Data explored through confirmatory regression analyses	There was a strong positive relationship between relatives' sense of guilt and emotional overinvolvement
Breitbart et al. (2009)	USA	Study 1: QUAL; study 2: descriptive longitudinal	21 relatives (15 mothers, 5 fathers, 1 wife) and the respective 21 patients	Not reported	Not applicable	Not applicable	Not applicable	Exploration of the relationship between: caregivers' perceptions of patient's agency, EE and the course of schizophrenia; Study 1: qualitative analysis of relatives' narratives. EE coded with CFI; Study 2: explored the interrelationship between the 3 variables. Measures: Brief Psychiatry Rating Scale, Present State Examination and Psychiatric Assessment Scale	High-EE relatives perceived the expression of symptoms as stemming from patient's agency more frequently than low-EE relatives did

CHAPTER 2 - WHAT DO WE KNOW ABOUT THE PROCESS OF FAMILY INTERVENTIONS FOR PSYCHOSIS? A SYSTEMATIC REVIEW

Smerud and Rosenfarb (2008)	USA	Descriptive	28 (12) patients and their relatives	Patients: 30.2	One monthly support group session	Not reported	Behavioural Family Therapy at home plus support group sessions (home and service based)	Family burden/ wellbeing and patients' symptoms	One early session of Behavioural Family Therapy was coded using the System for Observing Family Therapy Alliances	When relatives developed a positive therapeutic alliance, patients were less likely to show prodromal signs of relapse and to be re-hospitalized over a two-year follow-up; When patients developed a positive alliance, relatives became less rejecting and were less likely to feel burdened over a two-year period
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Note. QUAL = Qualitative study; CS = Comparative study; RCT = Randomised controlled trial; EE = Expressed emotion; CFI = Camberwell Family Interview

Studies comprehensively examining the process of an intervention

Bloch, Szmukler, Herrman, Benson, and Colussa (1995) conducted a comprehensive qualitative analysis of a controlled study of the effectiveness of a counselling programme for family caregivers. The analysis covered three dimensions: themes that arose throughout the sessions, main techniques used by the therapists and caveats for counsellors working in the field.

Regarding the first dimension, the examination revealed a wide range of themes. The most common was the intense need participants felt to share their own narratives of the caregiving experience. The other themes addressed were: coping mechanisms; the negative impact of the illness on family structure; and the social difficulties related to the onset of the illness, namely in dealing with mental health services. The analysis of the second dimension, comprising intervention techniques, was based on a screening of therapists' notes. This revealed a need to listen carefully to participants, acknowledging their experience, reinforcing their strengths and placing their role in a broader context. The codification of the third dimension revealed, as major caveats for counsellors, the difficulties in maintaining the focus of the group and dealing with the frustrations with the health care services.

The overall conclusion of this study was that FIP should be needs focused and therapists should be careful not to impose a rigid structure on the sessions. Counsellors should adopt multiple therapeutic roles such as supporting, reality testing, problem-solving and educating.

Studies on participants' opinions about the intervention received

The studies by Levy-Frank, Hasson-Ohayon, Kravetz, and Roe (2012) and Riley, Gregory, Bellinger, Davies, Mabbott, and Sabourin (2011) were comprehensive analyses of the views of the participants at the process-level of the interventions.

Levy-Frank et al. (2012) conducted a qualitative exploration of their efficacy study of two different approaches (Levy-Frank, Hasson-Ohayon, Kravetz, & Roe, 2011): a psychoeducational family intervention (PEFI); and a therapeutic alliance focused intervention (TAFI). In general, participants mentioned empathy, positive regard, guidance and advising as the main techniques that helped them to make positive changes. The authors also explored the perceived changes resulting from the group participation. The perceived sense of belonging and the use of social support and sharing as resources for caring, were the most common changes referred to, and were more prominent in the TAFI group. The acquisition of coping skills, the amelioration of guilt and shame, and the establishment of hope and motivation, were also changes reported in both groups.

In the Riley et al. (2011) study, 12 relatives were asked to participate in a focus group evaluating what happened in an eight-week educational group intervention. The thematic analysis showed five dimensions as the most relevant components of the programme, calling attention to the importance of the education provided by the professionals, the work with the emotional impact of the illness on the family, the opportunity for sharing their own experiences and the teaching to achieve a closer relationship with services.

The remaining nine papers of this category provide isolated data on what participants found helpful and unhelpful about the interventions, and what changes were promoted by the interventions.

Five studies showed that relatives valued information giving and education about the illness (Barrio & Yamada, 2010; Budd & Hughes, 1997b; Buksti et al., 2006; Mannion, Draine, Solomon, & Meisel, 1997; Sundquist, 1999). Buksti et al. (2006) highlighted the importance of the group leaders' attitude and the opportunity to listen to others as enhancers of the learning experience. Budd and Hughes (1997b) emphasised the importance of delivering handouts with the contents of the educational sessions as participants found it difficult to retain all the information in the sessions and it may be necessary for relatives to refresh their memory through reviewing this material. The Sundquist (1999) and Mannion et al. (1997) papers stressed the advantage of tailoring the information to the relatives' ongoing difficulties in dealing with patients' current behaviour. Finally, Barrio and Yamada (2010) emphasised the importance of adapting the information according to the relatives' background and culture.

The therapeutic alliance was the next most reported element in this group of papers (Cabral & Chaves, 2010; James, 2006; Stanbridge, 2003). James (2006) stressed the importance of humanity, warmth and confidence about the intervention as demonstrated by the therapists, namely in the engagement phase. Likewise, Stanbridge (2003) restates this, adding the therapists' competence on specific interventions as a major ingredient, and suggesting that a good therapeutic relationship is necessary but not sufficient for effectiveness. Cabral and Chaves (2010), working in a middle-income country, found that non-specific factors such as providing help and support may be of greater importance than information giving and education.

The focus on relatives' needs was also reported as an important issue. Stanbridge (2003) found that addressing relatives' needs is crucial at the engagement phase, with therapists paying attention to this when agreeing therapeutic aims with the group. Barrio and Yamada (2010) also found it significant to take into account relatives' background and culture when defining sessions' contents.

The opportunity for sharing was yet another domain in this set of papers (Buksti et al., 2006; Stanbridge, 2003). Strikingly, in the study of Buksti et al. (2006) relatives rated the opportunity of listening to others with similar problems as more important than sharing their own issues.

Other elements valued by the participants were: (1) the opportunity for problem-solving, namely on how to deal with patients' illness-related difficulties, with Mannion et al. (1997) emphasizing the opportunity for individualized problem-solving while Stanbridge (2003) highlighted the importance of shared problem-solving; and (2) the support received throughout the group (Barrio & Yamada, 2010; Budd & Hughes, 1997a).

Regarding self-perceived changes by the participants, two papers linked knowledge acquisition with the change in attributions towards patients (Barrio & Yamada, 2010; Budd & Hughes, 1997b), while Sundquist (1999) reported changes in increasing skills to deal with patient's behaviour and the identification of stress producing situations.

Comparative studies individualizing process-related variables

Tarrier, Barrowclough, Vaughn, Bamrah, Porceddu, Watts, and Freeman (1988) developed a complex study by comparing different techniques in four treatment groups.

Two of them were behavioural interventions with different strategies. One used enactive training techniques, which require active participation (e.g. role-playing), and the other using symbolic training (e.g. discussions and instructions). The third intervention group received education only and the fourth routine treatment. As major findings of this study, they found that education only is ineffective in preventing relapses, and that involving relatives in a behavioural intervention with their active participation in training, is the best technique to achieve positive outcomes in reducing relapses and regulating EE.

By contrast, two other studies comparing process-related variables (Birchwood, Smith, & Cochrane, 1992; Kane, DiMartino, & Jimenez, 1990) highlighted the importance of giving information to relatives. Birchwood et al. (1992) compared three different methods for delivering information and found that this is associated with therapeutic gains in knowledge about the illness, positive expectations about the relatives' role in treatment and less family distress. They also found that, at six months follow-up, the determinant for these outcomes was information-giving, irrespective of the method of delivery (i.e. post, video or group sessions). Kane et al. (1990) found that in a short programme psychoeducational techniques had a greater effect on satisfaction and the relatives' emotional state, as compared with support-oriented strategies.

Levy-Frank et al. (2011) reached different conclusions. As mentioned above, they compared the effectiveness of TAFI versus a family psychoeducational intervention adapted from Multifamily Group Therapy (McFarlane, 2002). The former was focused on developing a strong therapeutic alliance with the participants, while the latter was problem-focused, offering information and teaching communication skills. No differences were found between groups. For both interventions, at the post-treatment

phase, caregivers reported less burden, and perceived higher levels of quality of life and lower levels of psychiatric symptoms in their patients. Mediator variables were identified: therapeutic alliance and hope for a reduction in family burden, and reduced EE for psychiatric symptoms. Despite some limitations of the study (e.g. heterogeneity of patients' diagnoses; possible contamination of TAFI with educational material), a debate on technique-oriented interventions as compared to context-oriented interventions was introduced in the field of FIP.

Studies on the exploration of mediating variables related to FIP outcome

The majority of the studies on mediating variables were concerned with what can change EE. We found a review (Barrowclough & Hooley, 2003) reporting that attributions of the relatives about patients' behaviour may mediate EE. This was supported by other studies of this category that demonstrate what specific attribution-elements affect EE, namely: (1) patient's locus of control, agency and self-efficacy on their problematic behaviour (Bentsen et al., 1997; Breitborde, Lopez, & Nuechterlein, 2009); and (2) expectations about the patient's employment (Bentsen, Notland, Boye, et al., 1998).

The study by Bentsen, Notland, Munkvold, et al. (1998) reported work with relatives concerning guilt about the aetiology of the disease as a mediator variable. The remaining paper of this cluster showed that the therapeutic alliance may also be a major determinant on the efficacy of FIP (Smerud & Rosenfarb, 2008).

2.4.1 Core elements identified

Looking at the basic elements of each intervention, some trends can be identified (Table 3). Therapeutic alliance, support and education were valued across the cluster of papers regarding participants' opinions. This congruence is not possible to obtain in the comparative studies' group. Here we see different perspectives claiming, in a mutually exclusive way, greater relevance for therapeutic alliance (Levy-Frank et al., 2011), education (Kane et al., 1990; Birchwood et al., 1992) or coping skills training (TARRIER et al., 1988).

It is noteworthy that almost all studies suggested more than one element to be prominent, with the exception of studies on mediating variables, where the reframing of relatives' views about patients' behaviour and symptoms was deemed decisive.

Table 3
Level of prominence of the elements identified as being major elements in the interventions

Study	Elements Identified								
	Therapeutic alliance	Support	Sharing	Needs	Education	Reframing	Coping skills	Problem-solving	Guilt, loss and grief
<i>Studies comprehensively examining the process of an intervention</i>									
Bloch et al. (1995)	++	+++	+++	+++	+		++	+	
<i>Studies on participants' opinions about the intervention received</i>									
Barrio and Yamada (2010)		++		+++	+++	++	+		
Budd and Hughes (1997a)	++	+++			+	++			
Budd and Hughes (1997b)					+++	++			
Buksti et al. (2006)	++		+++		+++				
Cabral and Chaves (2010)	++	+++			+				
James et al. (2006)	+++	+++							
Levy-Frank et al. (2012)	+++	+++			++		+		+
Mannion (1997)		+++	++	+++	+			++	
Riley et al. (2011)		+	++	++	++				+++
Sundquist (1999)		+	+		+		+		
Stanbridge et al. (2003)	++	+++	++	+++		++		++	
<i>Comparative studies individualizing process-related variables</i>									
Birchwood et al. (1992)	+	+	+		+++				
Kane et al. (1990)					+++				
Levy-Frank et al. (2011)	+++								
TARRIER et al. (1988)					+		+++	++	

Studies on the exploration of mediating variables related to FIP outcome

Barrowclough and Hooley (2003)		+++	
Bentsen et al. (1997)		+++	
Bentsen et al. (1998a)		+++	
Bentsen et al. (1998b)			+++
Breitborde et al. (2009)		+++	
Smerud and Rosenfarb (2008)	+++		

Note. *Support* includes warmth, validation and positive regard; *Sharing* includes information about illness and ways to cope with patient's behaviour provided by other participants; *Needs* refers to tailoring the aims and content of the intervention accordingly to the needs reported by the participants; *Reframing* refers to work with relatives views about patient's behaviour and symptoms; and *Coping skills* includes information and training strategies on how to deal adequately with patient's behaviour. + means that the element was classified as being *important*; ++ as *prominent*; and +++ as *highly prominent*.

2.5 DISCUSSION

We conducted a comprehensive review of the relevant literature of studies on the process of FIP. We did not find any informative qualitative study explaining the process of the intervention in depth. Despite being identified by many authors (Cohen et al., 2008; Dixon et al., 2001; Lam, 1991; Leff, 2000; McFarlane et al., 2003), there remains a paucity of research in this area. The study by Bloch et al. (1995) was the only one to address this issue to a considerable extent. It reinforced the idea that FIP are complex interventions with a broad spectrum, showing that in practice, FIP must be flexible and shaped to the needs of the families. Overall, the conclusions of this study are scanty regarding the definition of the process of FIP.

The lack of research in the process of FIP also applies to quantitative data, as we only identified four comparative studies isolating process-related variables with the potential to establish individual linkages to the outcome (Birchwood et al., 1992; Kane, et al., 1990; Levy-Frank et al., 2011; Tarrier et al., 1988). Their conclusions are sparse because they point to three different directions when considering the prominence of the key-elements: i.e. therapeutic alliance; education and coping skills training.

An alternative way to identify prominent elements of an intervention is by seeking the opinion of the participants about this subject. We found a number of good studies in this area, the majority demonstrating the great importance of the humanist dimensions of the intervention. Relatives also tend to emphasise education and reframing, and surprisingly they do not consider coping skills training as highly relevant. From a first impression, this could be inconsistent with the conceptual descriptions and treatment manuals of some important FIP models such as Behavioural Family Therapy, which emphasises skills training techniques (including communication training and problem-solving). However this might be explained by the fact that despite being core elements they are not valued by the participants, or because not every family may need coping skills training.

Overall, the humanistic variables are the most reported as active ingredients of FIP, as many studies highlight the importance of education (e.g. Birchwood et al., 1992; Kane, et al., 1990; Budd & Hughes, 1997b; Buksti et al., 2006), while few others advocate on behavioural training (e.g. Tarrier et al., 1988). This difference in components' weights suggests different levels of intervention.

Our findings are consistent with the opinion of Liberman and Liberman (2003) who stated that there is no reason for one to think that more components in the intervention will necessarily mean better outcome.

On this subject, the "The Family Forum" (Cohen et al., 2008), developed a treatment heuristic based on the "principle of sufficiency". The lower intervention level starts with a family-friendly contact, and if necessary, the family will proceed to education sessions and if the relatives still demonstrate distress, or if the patients' state

is unstable, then there will be a need for their inclusion in an intensive programme involving formal skills training.

Common therapeutic factors: one of the most important components of FIP

Most of the papers summarised in this review outline the major contribution of common therapeutic factors to the effectiveness of FIP, namely therapeutic alliance, support and the opportunity for sharing (Table 2). This is consistent with the psychotherapy outcome research literature (Grencavage & Norcross, 1990; Wampold, 2001), where it is argued that a number of dimensions shared by almost all psychotherapies are major active ingredients, regardless of specific techniques used in the therapy. As suggested by the authors of the most important FIP models, it is crucial to establish a supportive and collaborative relationship with the participants (WFSDA, 1997). Levy-Frank et al. (2011, 2012) introduced the debate on whether the common therapeutic factors could be the sole determinants for the outcome of FIP. The overall conclusions of their comparative study (Levy-Frank et al., 2011) indicate that in some occasions this is true. There is considerable evidence showing that the human component of FIP may itself be an active ingredient for positive outcome.

The role of information-giving and education

Beyond common therapeutic factors, the delivering of information and education are other elements that have proved their worth. The study by Birchwood et al. (1992) shows that delivering of information alone can be effective in decreasing the stress in the family. Likewise, Kane et al. (1990) highlighted the importance of education over support-oriented techniques in shorter intervention programmes.

Education can be effective in reframing relatives' views about patients' locus of control and agency. Two studies on participants' opinions have demonstrated that education increases knowledge about the illness (Barrio & Yamada, 2010; Budd & Hughes, 1997b), which in turn leads to reframing. As shown in this review, reframing is a mediating variable in lowering or dealing with EE (Table 2). Therefore, education can be a major predictor of relapse prevention. However caution is needed in accepting this relation, as the evidence is limited (Lam, 1991).

Additionally, the majority of FIP models have a strong education component, which is highly valued by the participants (Barrio & Yamada, 2010; Budd & Hughes, 1997b; Buksti et al., 2006; Mannion et al., 1997; Sundquist, 1999). Thus, education may also play a part in engagement and support. It is likely that relatives perceive education as meaning that professionals are highly committed to helping them and appreciate their role of carers.

Practical and clinical implications: FIP as a stepped approach with levels of intervention

The majority of studies in this review reported more than one element as being important, and different combinations appeared throughout the synthesis of the studies. However, emphasis must be placed on the common therapeutic factors, and to some extent on education. The other elements of FIP seem to be additive in their contribution to effectiveness, particularly if they are tailored to the needs of the participants.

In some families it is possible to achieve positive outcomes without a great effort, just by developing a therapeutic alliance and giving support to the participants. The positive emotions then generated are a starting point not only for engagement, but

also as the first step for psychological transformations in the relatives, by increasing their self-esteem and mood. Sometimes this preliminary transformation may be enough for contributing to good clinical outcomes in the patients (Levy-Frank et al., 2011). On other occasions, therapists may need to go further by delivering education. Further ahead, they may need to work on coping skills, communication skills, problem-solving and other emotional issues. This process of transformation is congruent with Kuipers' view about the mechanisms of change of FIP (Kuipers, 2006), by emphasizing the emotional changes in relatives by improving their self-esteem, mood and coping skills.

The evidence we reviewed suggests that there is a core of components of FIP and a cluster of other techniques utilized only if necessary. FIP must be sensible programmes, delivered by professionals trained in evaluating families' needs and with the expertise to deliver different techniques moment-by-moment as they are necessary. However the effectiveness of each strategy in specific circumstances needs to be established.

2.5 CONCLUSIONS

To our knowledge this was the first systematic review aiming to explore the process of FIP based on empirical data, mostly qualitative, from studies of interventions as they occurred in the "real world". So far, this information was mostly based on conceptual descriptions and experts' opinions based on their knowledge and practice. We found that being in a therapeutic supportive relationship followed by education about the illness and later coping skills training, could be major active ingredients in different levels of intervention, according to families' needs. However, the knowledge

gap remains. While a step-by-step series of studies of the individual components of the variety of FIP is currently not feasible, there are other valuable research possibilities to consider. We are fortunate in having access to a unique data set, which would allow a qualitative analysis of the comparative efficacy of the various components in a long-term group of family carers of relatives with schizophrenia (Leff et al., 1982; Leff et al., 1985) run by two experienced therapists. The detailed accounts of the interactions in this group between the participants and the therapists, augmented by clinical records of the patients, provide a rich source of data. By undertaking this, we hope to identify the salient clinical interventions that contributed to the effectiveness of that particular FIP. This work will be described in Chapter 3.

The findings of this review together with our qualitative analysis of the Leff and collaborators trial (Leff et al., 1982; Leff et al., 1985) should achieve the identification of linkages between process and outcome, and a better understanding of changes attributable to specific strategies. Such essential knowledge may lead to a simpler straightforward model, which could overcome the current problems of dissemination of FIP (Cohen et al., 2008; Glynn, 2012; Leff, 2000).

CHAPTER 3

A QUALITATIVE ANALYSIS OF AN EFFECTIVE FAMILY INTERVENTION FOR SCHIZOPHRENIA

Study 2

3.1 BACKGROUND

The debate on the definition of the key-elements of FIP is far from its ending. Although there have been contributions outlining the components of FIP (Kuipers, 2006; Liberman & Liberman, 2003; McFarlane, 1991; World Fellowship for Schizophrenia and Allied Disorders, 1997), authors still raise the need to identify exactly the active ingredients of FIP (Cohen et al., 2008; Dixon et al., 2001; Lam, 1991; Leff, 2000; McFarlane et al., 2003).

Similar to our systematic literature review described in Chapter 2, but with a different scope, one recent literature review made very good attempts in increasing the knowledge about the process of FIP (Sin & Norman, 2013). The authors found evidence supporting that education and coping skills training are essential components of FIP. They also stressed the need for interventions to be flexible and to give opportunity for relatives to share their experiences.

In our systematic review, we also had found evidence supporting the key-elements demonstrated by Sin and Norman (2013). However, we additionally had found that other less discussed components, such as the common therapeutic factors, could also be major active ingredients. We suggested a stepped-model of intervention with different levels according to relatives' needs.

The study from Sin and Norman (2013) and our systematic review, both confirmed previous concerns and emphasised the lack of research on the process of FIP.

To identify the key-elements of the process of FIP, one should provide qualitative research alongside efficacy studies (Higgins & Green, 2011). In Chapter 2 we attempted to search for qualitative research about the process of effective FIP. Our

search resulted in almost an absence of this kind of studies. We found a single paper comprehensively exploring the process of FIP (Bloch et al., 1995). In this study the authors unveiled a wide range of themes in the intervention, concerning personal, coping, family and social aspects of the caregiving experience. The conclusions were that FIP should be needs focused and that therapists must assume multiple roles in the programme, with efforts being made towards validation and emotional support. However, the overall conclusions of the Bloch et al., (1995) study were scanty. Therefore qualitative research regarding the process of FIP is promising field.

In the present study, we will now describe an analysis of historical and highly relevant material by examining the intervention records of the clinical trial by Julian Leff and collaborators (Leff et al., 1982; Leff et al., 1985). The results of this trial were one of the largest effects of FIP ever found on the course of schizophrenia (Pitschel-Walz et al., 2001). The content of these intervention records has never been analysed and offers an outstanding opportunity to understand what happened in the process of that treatment programme.

3.2 AIMS

We aimed to find out which were the most used therapeutic strategies in the intervention programme. As secondary aims, we expected to provide a basis for elaborating on the usefulness of different strategies; to explore the differences between the strategies addressing high EE relatives and those for low EE ones; and to isolate variables related to the process that may be manipulated in future research.

3.3 METHODS

3.3.1 Data Collection

Data were recorded during the clinical trial of Julian Leff and collaborators between 1977-82, described elsewhere (Leff et al., 1982; Leff et al., 1985). This trial evaluated the efficacy of a family intervention for schizophrenia by manipulating relatives' EE. The method combined individual family sessions, and relatives groups sessions, and was later described in more detail (Kuipers et al., 2002).

Data was composed by transcripts of the audio-tapes of the 85 relatives group sessions (from a total of 86 sessions conducted; i.e. one missing data) and 25 single-family home sessions. The group sessions were delivered every fortnight at the service, while the single-family home sessions did not have a schedule. For each session, the therapists transcribed the main themes and interactions. The content of the records included direct speech sentences and clinical comments. A structure was applied to each session, i.e. all records included the number and duration of the session, the name of the participants attending, the name of the therapists, aims, general observations, discussion and comments.

3.3.2 Participants of the Clinical Trial of Leff and Collaborators

Subjects included in the clinical trial under analysis were relatives of patients suffering from schizophrenia. Recruitment had been carried out during psychiatric admissions at three hospitals in London. To meet inclusion criteria, patients had to live continuously with the caregiver for three months before admission, and spend more than 35 hours per week in face-to-face contact with this or more relatives.

Twenty-two relatives of 19 patients had participated in the group sessions. Seventeen were female. Sixteen were parents (of six daughters and ten sons), and the other six were spouses (two wives and four husbands).

The mean number of participations was 14 sessions (min. 1; max. 41) from a total of 309 attendances. The mode number of participations was 18.

Only five participants had low EE, being responsible for only 10% of the total of the attendances in the group. The mean participation of low EE relatives was 6 sessions (min. 1; max. 18), with a mode of attendances of one session. The mean of attendances of high EE relatives was 18 sessions (min. 4; max. 41) and the mode was also 18 sessions.

As seen by the mean of attendances, participants did not come to the group all at the same time. The group sessions were opened to new participants to join the group. On the other hand, some participants dropped-out or judged their participation to come to an end with the agreement of the therapists. On this subject, there was a major change of the participants on session 35. On the preceding sessions, almost all participants were new to the group. In Appendix 1, a list of attendances by participant and session is presented.

Only eight relatives were included in the single-family home sessions that we analysed. These participants were all high EE relatives. The mode number of sessions per participant was two and the maximum number of sessions was seven.

Although we only had data of these single-family sessions, every participant additionally received, at least one home session dedicated to education about the illness (Leff et al., 1982). Those sessions were not available for analysis.

3.3.3 Data Coding

Before starting the coding process, the material was organised and pre-analysed. The original records had been typewritten and needed to be transcribed electronically to a MS Word® Software format (Microsoft). This process allowed the author a floating reading that started to bring awareness about the better qualitative approach to use in this study.

After several team meetings (including the supervisors of this thesis and with two qualitative research experts), we chose to apply a deductive mechanical approach, that is the analysis of the content of the data into previously defined categories (Bardin, 2004; Bradley, Curry, & Devers, 2007). This decision was based on the extension of the records, and, more important, because there was considerable evidence already available about the possible categories of information that it would be possible to find in the records. We based ourselves on the intervention manual (Kuipers et al., 2002) and on our systematic literature review about the process of FIP, as described in Chapter 2, to outline a comprehensive list of categories. This list was discussed and refined. Our concern was to build categories equilibrating specificity and comprehensiveness. We intended to avoid a code structure too wide to be feasible. The list of categories was eventually adjusted, and formed the initial code structure, with conceptual codes that matched therapeutic strategies. These codes were considered the nodes for the coding process later on.

The next step was to construct an operational definition for each conceptual code. This process enabled the definition of the final code structure, with 15 mutually exclusive categories, presented in Appendix 2. These categories formed the basis for the content analysis. In Table 4, an abbreviated form of this code structure is presented.

Table 4
List of categories of the code structure

A- Therapeutic Alliance
B - Emotional Support
C - Needs Addressing and Sharing
D – Group Dynamics
E – Education (Tailored, General, Shared and Unknown)
F - Coping Skills and Advice
G- Problem Solving
H – Modelling
I – Reframing
J - Dealing With Emotional Upset
K – Dealing With Anger, Conflict And Rejection
L – Dealing With Overinvolvement
M – Working With Grief
N – Working With The Family's Sense Of Stigma
O – Getting absent family members involved

Finally, the code structure was applied into practice to code the records. Data were managed and coded using the NVivo® version 10 software (QSR International) using a double independent coding process. Two investigators independently read each session and selected the sentences describing a code and dropped its content into the respective nodes (which resembled the code structure).

The coding was inserted on the participant that was receiving the strategy. For example if someone in the group was giving advice to other participant, the strategy was coded on the person who received the advice. When strategies were not specific to one person, coding was made to the corresponding group of participants. When strategies were group targeted (i.e. non-individual), coding was made to all participants.

Records were classified in the NVivo® (QSR International) by session and by participant. This means that we could document all strategies coded, including their relationships with the respective session and participant. With this process, we were able to understand which strategy was used, in each session, with a certain participant.

3.3.4 Validity and Reliability

The validity of the coding process was first guaranteed by having two investigators (the author and a research assistant), both clinical psychologists with experience and knowledge in the field. Notwithstanding, the first had higher experience in conducting FIP. A session was dedicated for the two investigators to have the opportunity to discuss the coding process, sorting out examples for each category. Agreement on the coding process was achieved.

The formal coding was then initiated and these investigators independently read all the records and identified the emergent therapeutic strategies, coding them into the previously defined categories. Afterwards, the team meets to review discrepancies, resolving differences by discussion and negotiated consensus. We used a consensus model (Bradley et al., 2007), discussing and re-examining coding discrepancies. If no agreement was reached on coding, a third senior researcher was consulted. In the independent coding we reached a moderate level of inter-rater reliability based on the most used taxonomies (Hruschka et al., 2004). Eventually, total agreement was achieved after discussing the items. This process required extensive work because of: (1) the large number of categories we had in the coding process; and (2) the large extension of the records.

We acknowledged qualitative research criteria on reliability (Armstrong, Gosling, Weinman, & Marteau, 1997; Hruschka et al., 2004) by: (1) providing independent coding in the content analysis; (2) assessing and controlling consistency between observers; (3) defining the study operations of the coding process; (4) specifying an operational definition for each category; (5) conducting line-by-line analysis to fulfil fittingness; and (6) ensuring transparency and confirmability by keeping memo writing of the coding process.

Validity was mainly addressed: (1) by guaranteeing that the observers had knowledge in the field; (2) by revising the richness and uniqueness of the records; (3) by ensuring the supervision from a senior author, expert in the field; and (4) by certifying the relevance and pertinence of the records.

3.3.5 Data Analysis and Synthesis

After the coding process, we created enumerating rules to transform words into numbers, and therefore, reaching an inventory of the coding process (Bardin, 2004). Data were exported from the NVivo® software (QSR International) to an MS Excel® (Microsoft) file, and were organised. A database was created with multiple entries, quoting the strategies by session and participant (i.e. 15 strategies crossed with 22 participants crossed with 85 sessions).

The process of analysis began by counting the frequencies of each category in overall and in detail by participant and session. Graphs and relationships between the categories were outlined. In-depth analyses were performed to find out the most used therapeutic strategies, the usefulness of the different strategies throughout the sessions,

and to evaluate if there were differences between the nature of the strategies used with high-EE relatives as compared with those with low-EE.

Besides descriptive statistics we also used test of hypothesis to ascertain if the differences we observed were significant. Addressing the complexity of our data and our aims on conceiving a longitudinal view of the process, we performed analyses using generalised linear models, namely generalised estimating equations, which are considered as semiparametric regression techniques. This model creates an algorithm to accommodate correlated data. The algorithm calculates the probability of a certain parameter to occur in the subsequent observations (Diggle, Heagerty, Liang, & Zeger, 2002). In fact, in the present study, we were interested in finding out if a certain strategy is more prone to happen in the beginning or in the end of the intervention programme.

All statistical analyses were performed using the SPSS® version 20 statistical software (IBM Corp.).

3.3.6 Ethical Considerations

Formal ethical approval for this secondary analysis was not deemed necessary. Written formal consent was obtained from the participants during the clinical trial including for this purpose, between 1977 and 1982, following ethical approval from the Medical Research Council's Social Psychiatry Unit in London/ Institute of Psychiatry, King's College London.

3.4 RESULTS

3.4.1 Relatives Groups

The most used strategies in the relatives groups of the intervention programme were: (1) needs addressment and sharing – corresponding to 21% of all strategies used in the intervention; (2) coping skills and advice – 15%; (3) emotional support – 12%; (4) dealing with overinvolvement – 10%; and (5) reframing relatives’ views about patients’ behaviours – 10%. Figure 2 presents the overall frequencies for each strategy.

Figure 2

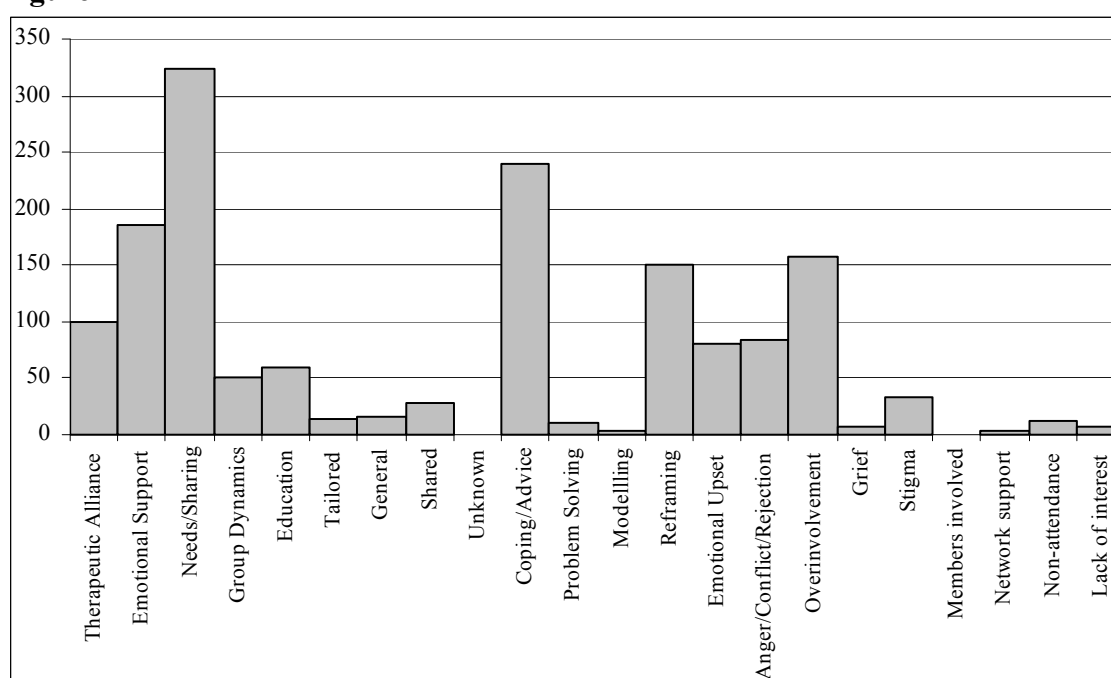


Figure 2. Overall frequencies for each therapeutic strategy in the relatives groups.

The overall frequencies also show that some therapeutic strategies were only marginally used during the group sessions. For example, strategies to work on grief, problem-solving and modelling had almost a null proportion. Other strategies such as education about the illness, dealing with emotional upset, dealing with anger, conflict

and rejection, and dealing with the family sense of stigma, were in the mid range, having each one the proportion of 5% of the all strategies.

Regarding education about the illness, the subcategory with the greater proportion, was education shared between participants (i.e. participants give information about the illness to other participants), contributing with 48% of all education strategies used in the intervention.

Longitudinal analysis by therapeutic strategy and session

The longitudinal analysis of each strategy throughout group sessions, showed some variations for almost all categories. We focused our analysis on the most used strategies, as they offered more information about what happened in the intervention. To understand data on a longitudinal basis, we had to split the analysis in two different phases, because of the change of the set of participants in the middle of the programme (as mentioned above). We analysed the results separately, from session 1 until session 35 (Group A), and another group from session 36 to session 86 (Group B).

By analysing the distribution of frequencies, the categories of needs addressment/ sharing, coping skills/ advice, and emotional support seem to have a very irregular pattern. These therapeutic strategies were frequently used in almost all sessions, however with marked highs and drops. This is especially true with needs addressment/ sharing, as shown as shown in Figure 3. The highest results of needs addressment/ sharing seem to be associated with high scores of coping skills/ advice (Figure 4), and immediately followed by emotional support, as seen in Figure 5. In fact, needs addressment/ sharing was positively correlated with coping skills/ advice $r(394)=.35$, $P<0.0001$, and with emotional support $r(394)=.29$, $p<0.0001$. In sum, when

needs addressment/ sharing had the highest value, there was a tendency for coping skills/ advice, and emotional support, also to increase.

Figure 3

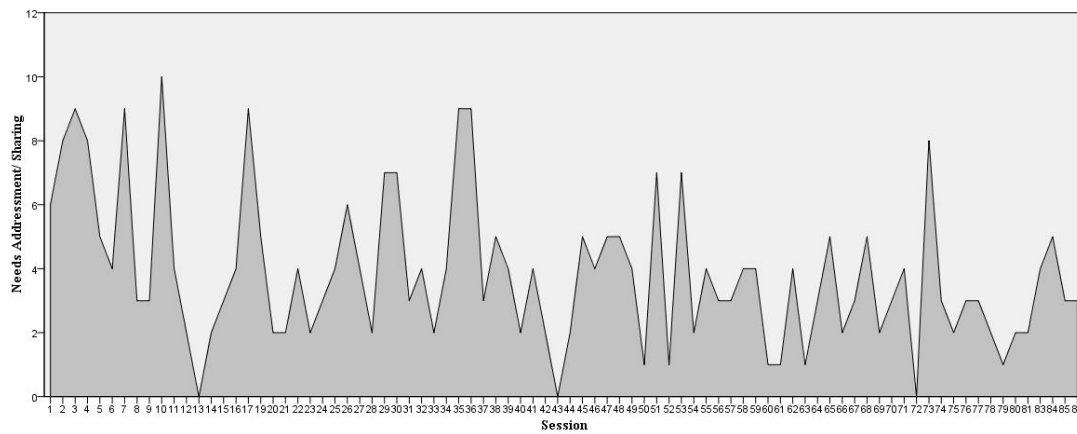


Figure 3. Frequencies of the category “Needs Adressement and Sharing” throughout sessions.

Figure 4

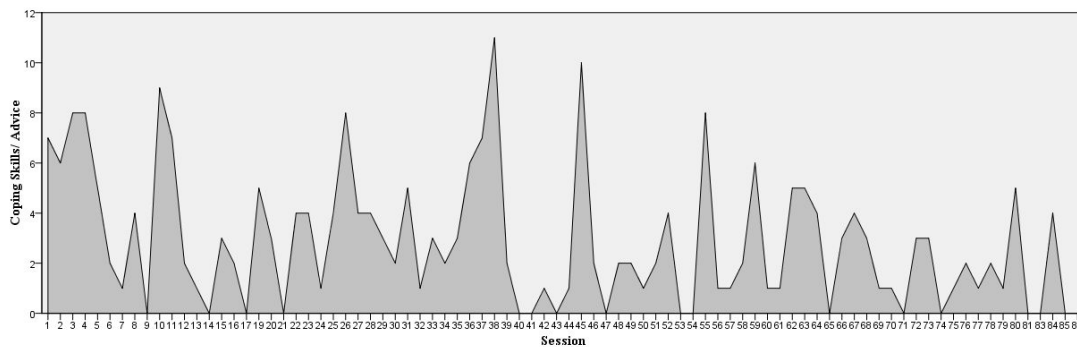


Figure 4. Frequencies of the category “Coping Skills and Advice” throughout sessions.

Figure 5

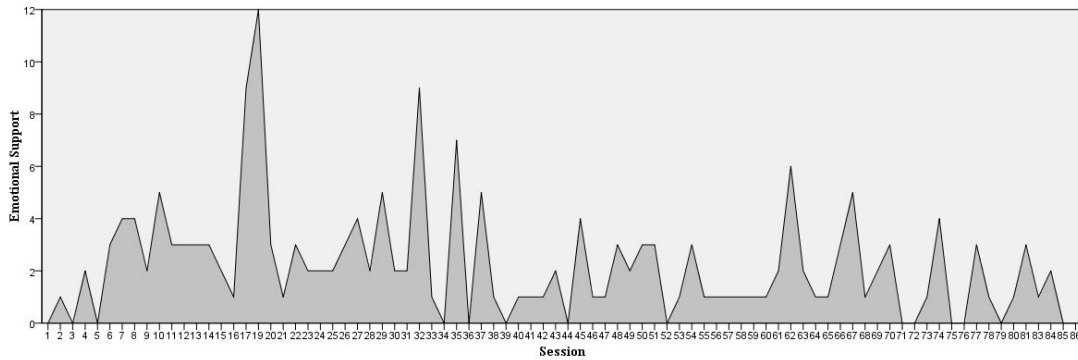


Figure 5. Frequencies of the category “Emotional Support” throughout sessions.

By analysing the frequencies in Group A and Group B, we found that strategies to regulate group dynamics and education, had the tendency to occur more often in the beginning of the programme (Figures 6 and 7).

Regarding education, on Group B, it was also frequent for this strategy to occur on the final of the first quarter and on the final the third quarter of the group (i.e. sessions 44 to 55, and 65 to 70). This happened at the same time as Group B was receiving new members.

Figure 6

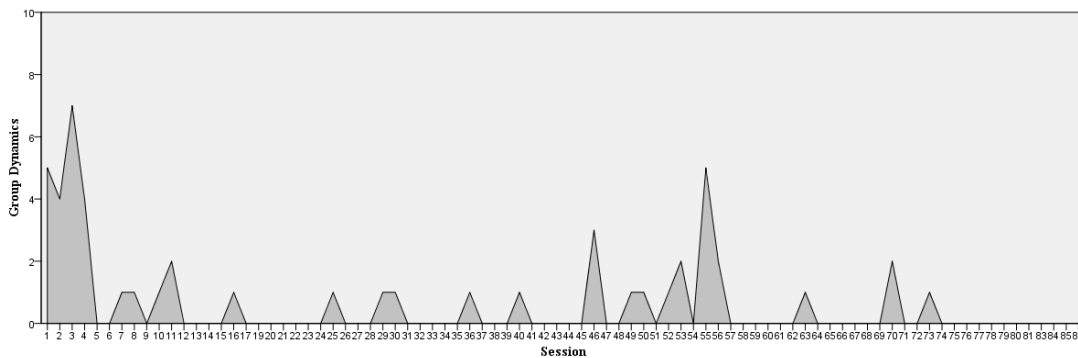


Figure 6. Frequencies of the category “Group Dynamics” throughout sessions.

Figure 7

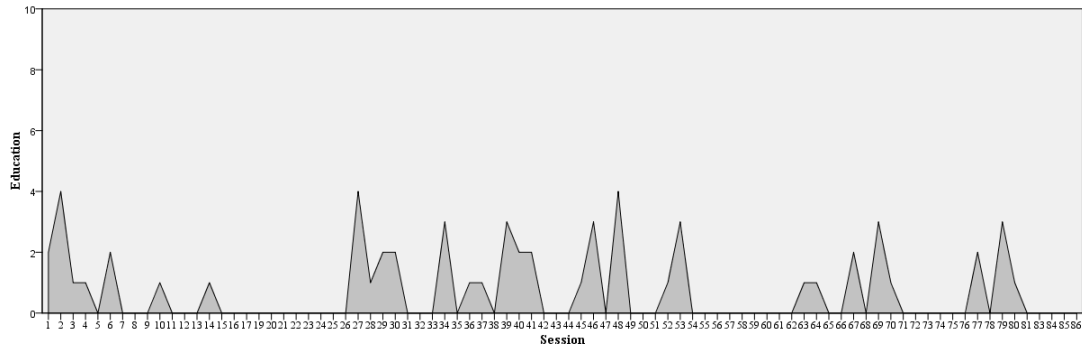


Figure 7. Frequencies of the category “Education” throughout sessions.

Regarding therapeutic alliance (Figure 8), it was possible to observe a regular pattern with the presence of very circumscribed elevations in certain sessions, namely on sessions 19, 27, 43 and 74.

Figure 8

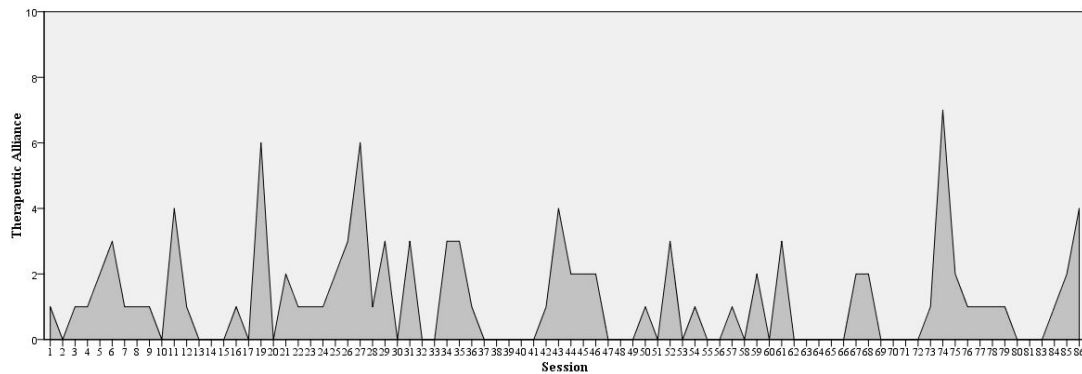


Figure 8. Frequencies of the category “Therapeutic Alliance” throughout sessions.

The remaining therapeutic strategies seem to occur more often in the middle and at end of the intervention programme, namely: (1) dealing with overinvolvement; (2) dealing with anger, conflict and rejection; (3) dealing with emotional upset; and (4) reframing relatives’ views about patients’ behaviours (Figures 9, 10, 11 and 12).

Figure 9

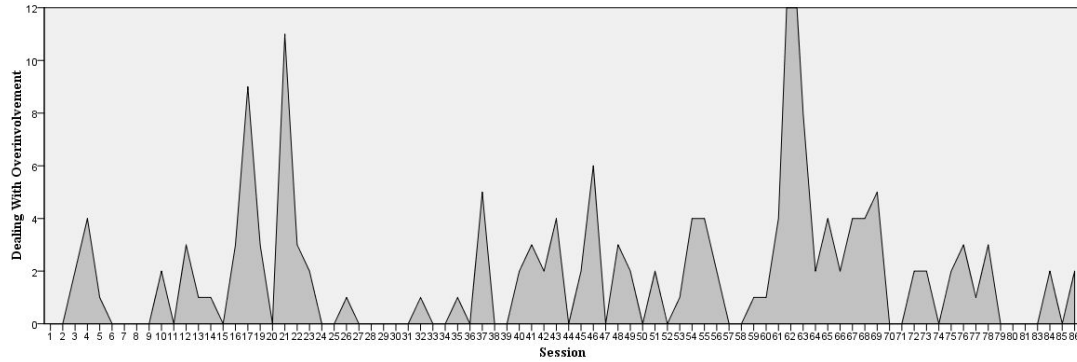


Figure 9. Frequencies of the category “Dealing with Overinvolvement” throughout sessions.

Figure 10

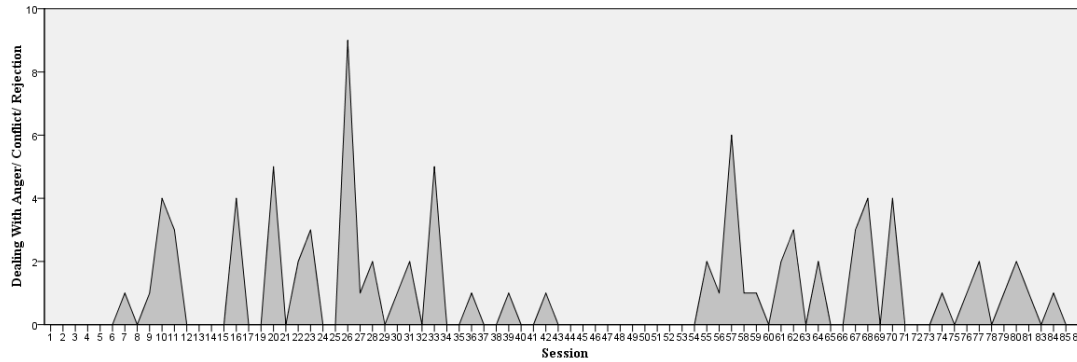


Figure 10. Frequencies of the category “Dealing with Anger, Conflict and Rejection” throughout sessions.

Figure 11

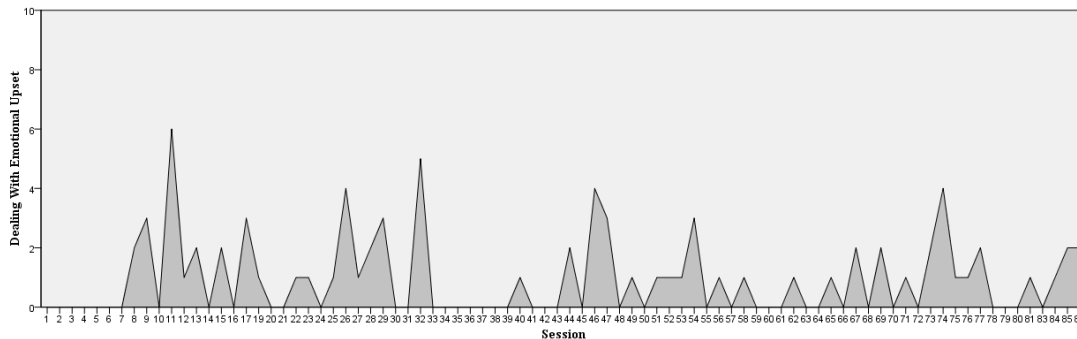


Figure 11. Frequencies of the category “Dealing with Emotional Upset” throughout sessions.

Figure 12

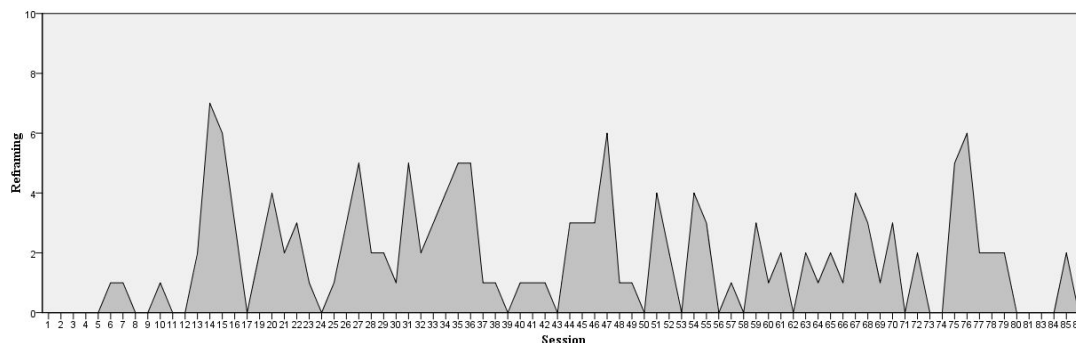


Figure 12. Frequencies of the category “Reframing” throughout sessions.

We also analysed the comparison of the distributions between: education; coping skills/ advice; dealing with anger/ conflict/ rejection; dealing with emotional upset; dealing with overinvolvement; and reframing. Figure 13 allows a better understanding of this comparison.

As mentioned above, education was highly incident at the beginning of both Groups A and B. This strategy seems not to be associated with any other strategy.

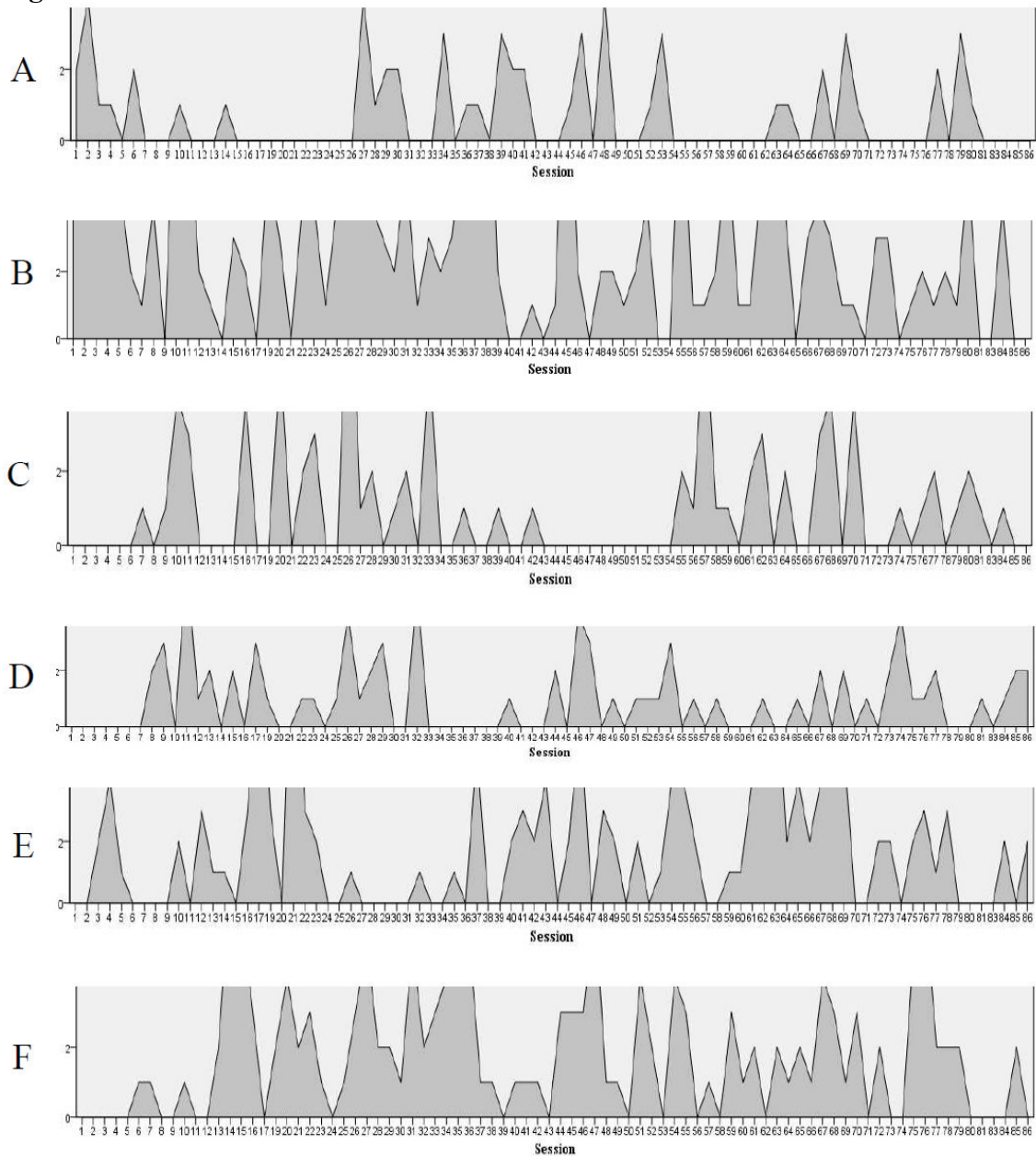
On the other hand, coping skills/ advice was fluctuating throughout sessions, We found an association between coping skills/ advice and reframing: Group A, $r(394)=.25$, $p<.01$; Group B, $r(394)=.28$, $p<.0001$.

The comparison of reframing with other strategies showed that this strategy was associated with dealing with anger/ conflict/ rejection, especially in Group A $r(394)=.41$, $P<0.0001$. In Group B, reframing was also associated with: dealing with anger/ conflict/ refection; dealing with emotional upset; and dealing with overinvolvement.

All other strategies in this comparison were prominent after the first quarter of both groups. To note a slightly difference for dealing with overinvolvement. This

strategy seemed to occur very early in both groups as compared with: dealing with anger/ conflict/ rejection; dealing with emotional upset; and reframing.

Figure 13



A – Education; B – Coping Skills and Advice; C – Dealing with anger, conflict and rejection;
 D – Dealing with emotional upset; E – Dealing with emotional overinvolvement; F - Reframing

Figure 13. Comparison of distributions between strategies.

To evaluate the significance of the observed differences in the distribution of frequencies, we conducted tests of hypotheses comparing the differences throughout the life span of the group. We calculated Generalised Estimating Equations placing each strategy as dependent variable and the number of the session as covariate. The analyses discriminated Group A and Group B. In Table 5 the results of the Generalised Estimating Equations analysis are presented, for Groups A and B.

Table 5
Probability of a strategy to occur in the following sessions

Therapeutic Strategy	Group A				Group B			
	p-value		Exp(B)-1		p-value		Exp(B)-1	
Therapeutic alliance	0.043	*	0.040	↑	0.524	n.s.	-	-
Emotional support	0.035	*	0.038	↑	0.195	n.s.	-	-
Needs assessment and sharing	0.592	n.s.	-	-	P<0.0001	****	0.014	↓
Group dynamics	P<0.0001	****	0.149	↓	0.02	*	0.040	↓
Education (all)	0.822	n.s.	-	-	0.012	*	0.032	↓
Education (tailored)	0.248	n.s.	-	-	0.047	*	0.057	↓
Education (general)	-	-	-	-	0.004	**	0.042	↓
Education (shared)	0.350	n.s.	-	-	0.022	*	0.034	↓
Coping skills and advice	0.814	n.s.	-	-	0.002	**	0.028	↓
Problem solving	0.002	**	0.102	↓	0.875	n.s.	-	-
Modelling	0.137	n.s.	-	-	-	-	-	-
Reframing	P<0.0001	****	0.074	↑	0.070	n.s.	-	-
Dealing with emotional upset	0.020	*	0.035	↑	0.461	n.s.	-	-
Dealing with anger/ conflict/ rejection	0.046	*	0.056	↑	0.044	*	0.013	↑
Dealing with overinvolvement	0.753	n.s.	-	-	0.025	*	0.013	↓
Working with grief	0.172	n.s.	-	-	-	-	-	-
Working with the family's stigma	0.521	n.s.	-	-	P<0.0001	****	0.043	↓
Getting absent family members involved	-	-	-	-	-	-	-	-
Involving network for support	0.459	n.s.	-	-	-	-	-	-
Coping with non-attendance	P<0.0001	****	0.086	↑	0.261	n.s.	0.036	-
Coping with lack of interest in meetings	P<0.0001	****	0.081	↓	P<0.0001	****	0.211	↓

Note. Exp(B)-1 reflects the probability of the strategy to occur in the following sessions

↑ probability increases; ↓ probability decreases

n.s. not significant; * significant; ** very significant; *** highly significant; **** extremely significant

Table 5 shows some differences in both groups. However, there was consistency on the evidence that strategies aiming to regulate group dynamics, and coping with the lack of interest in the meetings (a less frequent strategy), were decreasing throughout the group sessions. Likewise, in both groups, it was proved significant that the occurrence of dealing with anger/ conflict/ rejection tends to increase overtime.

In Group A, it was possible to observe that emotional support and therapeutic alliance tend to increase their likelihood in the sessions. The same could be observed with dealing with emotional upset and reframing (the later being extremely significant). Two less frequent strategies also had some variations: problem solving, decreased; and coping with non-attendance, increased.

In Group B, the following strategies decreased overtime: needs addressment/ sharing; education; coping skills/ advice; dealing with overinvolvement; and working with the family sense of stigma (less frequent).

Analysis of the strategies tailored for each participant

As mentioned above, there was a large difference between the number of participants with high EE and those with low EE. Additionally low EE participants attended considerable few sessions. Therefore, we had to be cautious on exploring these data. The overall counting of frequencies was not a good way to synthesise these results. However, the analysis of the distributions quoting the use of each strategy by participant made possible to find some valuable information.

As seen in Figures 14, 15, 16 and 17 there was a tendency for some participants to receive more therapeutic strategies as compared to others. This was particularly

found with emotional support, needs addressment/ sharing, coping skills/ advice and reframing, with P6 and P9. The same happened with less intensity with P2, P13, P14 and P19. These participants were all high EE.

Figure 14

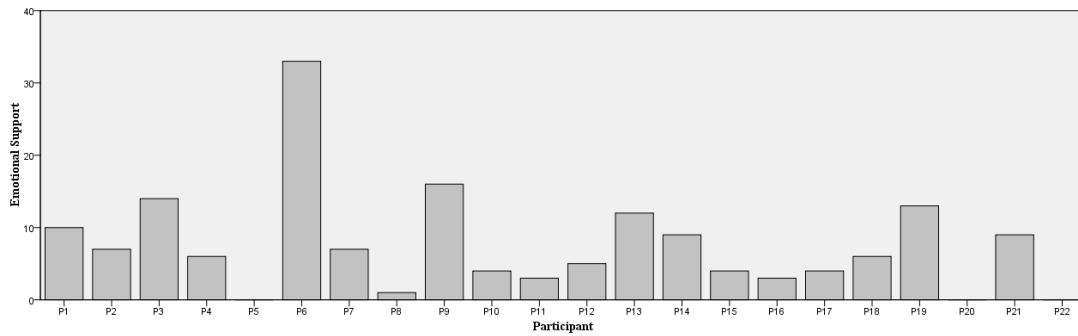


Figure 14. Frequencies of the category “Emotional Support” for each participant.

Figure 15

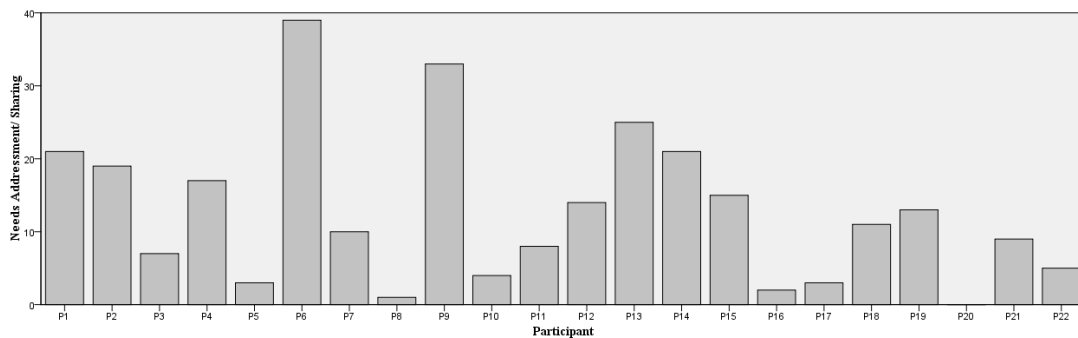


Figure 15. Frequencies of the category “Needs Addressment and Sharing” for each participant.

Figure 16

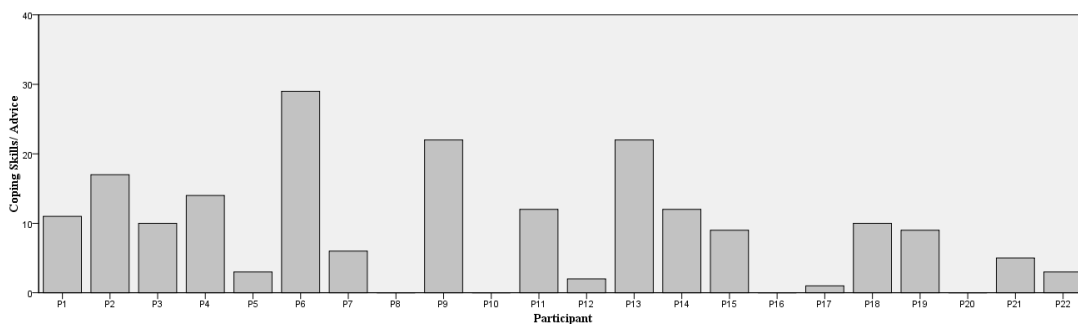


Figure 16. Frequencies of the category “Coping Skills and Advice” for each participant.

Figure 17

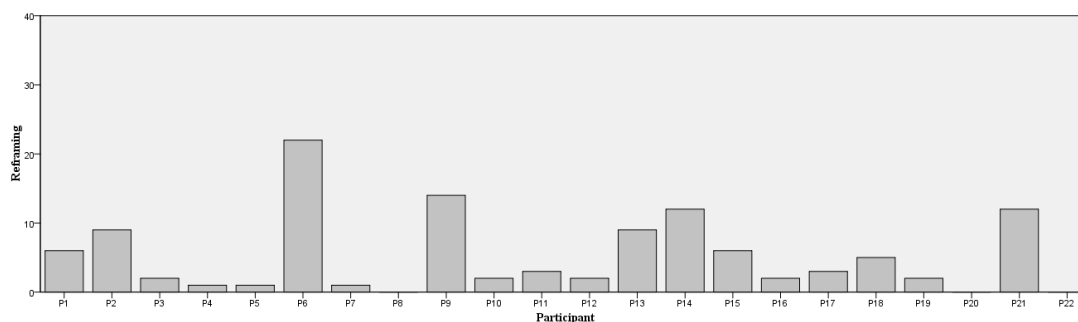


Figure 17. Frequencies of the category “Reframing” for each participant

Concerning low EE participants, we focused the analysis on P3 and P7, as they were responsible for 88% of all attendances amongst low EE relatives. Two featured results were observed with P3 and to some extent with P7. These participants received considerable amounts of emotional support (Figure 14) and, particularly, received high doses of therapeutic alliance oriented strategies (Figure 18).

Figure 18

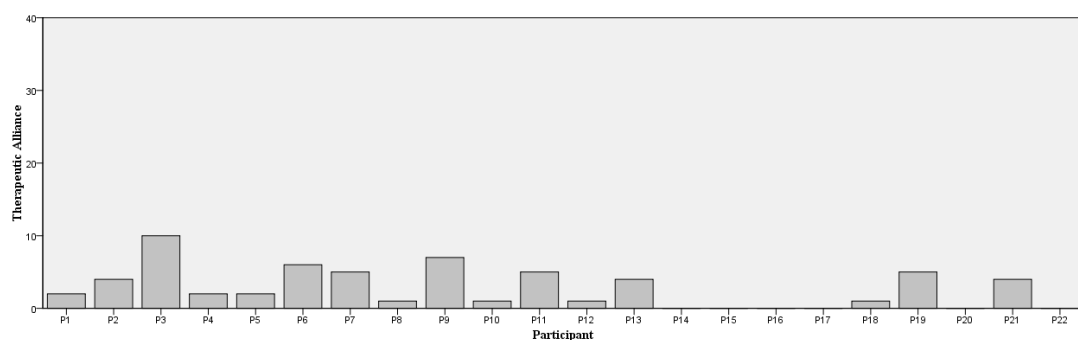


Figure 18. Frequencies of the category “Therapeutic Alliance” for each participant

By analysing the frequencies of education by participant, we found that even high EE participants, that invariably received large amounts of other strategies, as compared with low EE, had narrow values on this category (Figure 19).

Figure 19

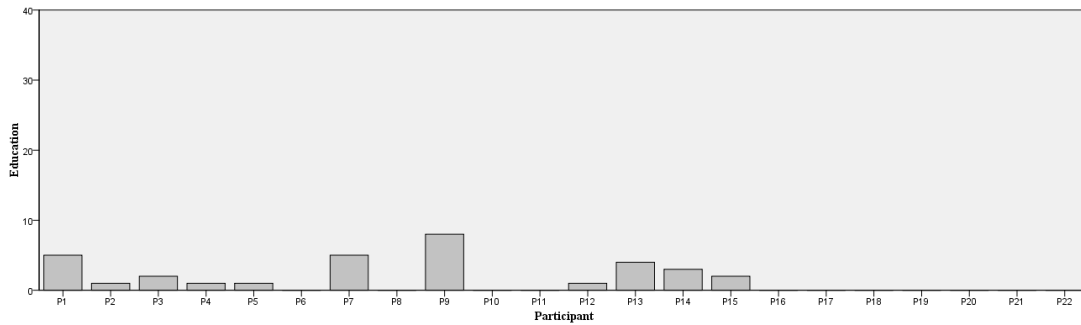


Figure 19. Frequencies of the category “Education” for each participant.

The analysis of the remaining prevalent categories, showed another interesting result. Dealing with overinvolvement, was high with some intercalated participants P1 and P2 (couple), P6, P14, P18 and P21 (Figure 20). Except for P6, these participants were all parents.

Figure 20

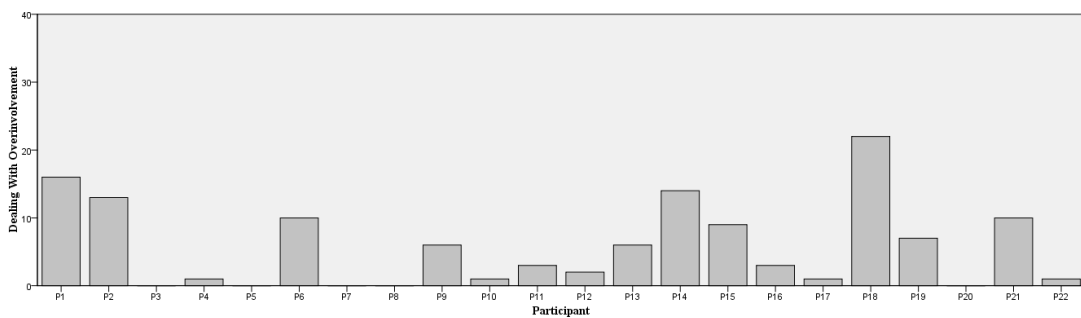


Figure 20. Frequencies of the category “Dealing with Overinvolvement” for each participant.

Regarding dealing with anger/ conflict/ rejection and dealing with emotional upset, P6, P13 and P21 had received the great bulk of these strategies (Figures 21 and 22).

Figure 21

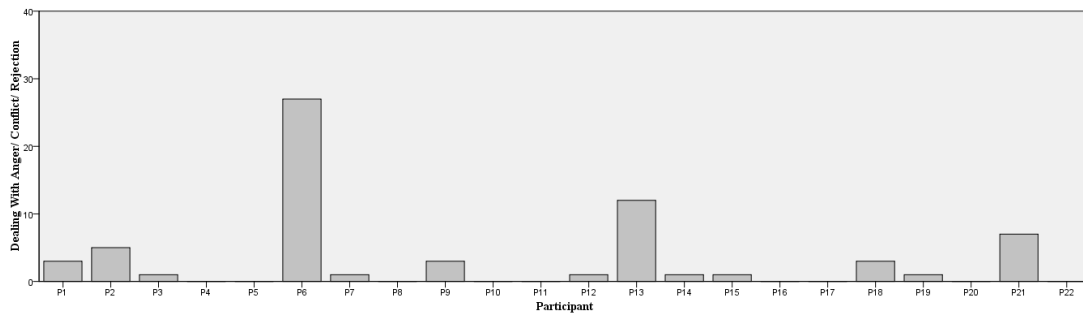


Figure 21. Frequencies of the category “Dealing with Anger, Conflict and Rejection” for each participant.

Figure 22

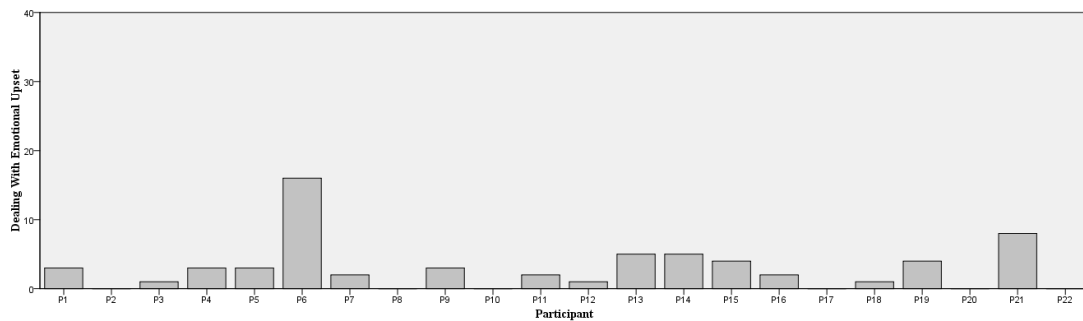


Figure 22. Frequencies of the category “Dealing with Emotional Upset” for each participant.

3.4.2 Single-Family Home Sessions

The most used therapeutic strategies in the single-family home sessions were (Figure 23): (1) dealing with overinvolvement – corresponding to 33% of all strategies used in the home sessions; (2) coping skills and advice – 22%; and (3) reframing and dealing with anger, conflict and rejection – both equally with 10%.

Figure 23

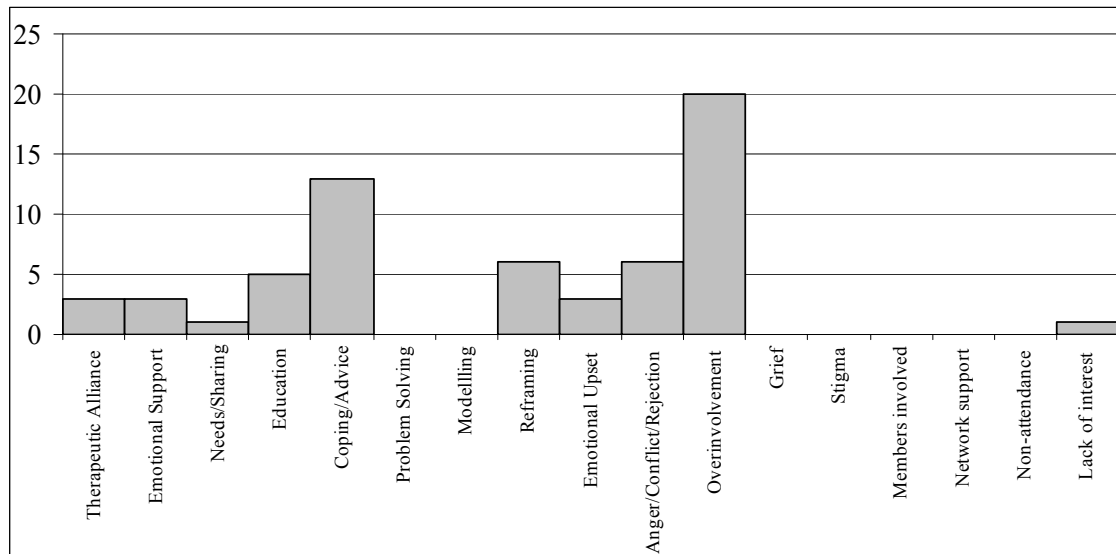


Figure 23. Overall frequencies for each therapeutic strategy in the single-family home session.

The analysis of the use of each strategy by participant (Figure 24) revealed that almost every participant received dealing with overinvolvement, except P11 and P21. P11 received plenty of coping skills/ advice, as well as P17. P21 received only dealing with anger/ conflict/ rejection. P1 was the one who received more education and P2 was highest on dealing with emotional upset.

Figure 24

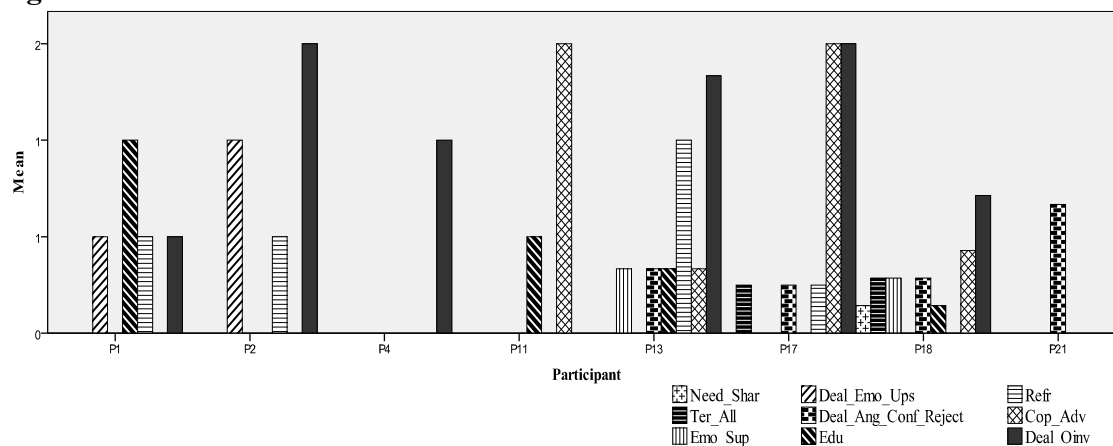


Figure 24. Mean value of each therapeutic strategy by participant, in the single-family home session.

3.5 DISCUSSION

We completed a comprehensive qualitative analysis of one of the most effective clinical trials of FIP ever conducted (Leff et al., 1982; Leff et al., 1985; Pitschel-Walz et al., 2001). This analysis relied on detailed clinical records. These data were coded into categories, which resembled therapeutic strategies, using a structure. For each session, categories were counted by participant.

In this study, we faced an imbalance between the number of group sessions and the number of single-family home sessions. This could be judged as a study limitation. However, there is evidence showing that in order to understand what is contributing for positive outcomes when delivering this approach, a focus should be placed on the relatives groups. In fact, years after the first clinical trial that we analysed, in another study (Leff et al., 1989), the same team led by Julian Leff, found that the intervention comprising only relatives groups, had a similar outcome when compared with the combined method.

In the following sections, we will discuss the major findings of our analysis, trying to answer to the questions beneath the aims of this study.

3.5.1 Which Were the Most Used Therapeutic Strategies in the Intervention?

The analysis revealed that, in this intervention programme, therapists gave priority (in the group sessions) in creating moments in which relatives could express their needs and share their difficulties about caregiving experiences. This is consistent with the findings by Bloch et al., (1995) that highlighted the importance of needs

addressment of FIP programmes. From a practical perspective this involves: (1) asking relatives directly for their difficulties; (2) setting the aims of the intervention based on relatives' needs; and (3) creating an atmosphere in the group that allows relatives to share their own difficulties spontaneously.

The second most used therapeutic strategy was the enhancement of relatives' coping skills and providing advice on how to cope with patients' behaviours. In practice, focusing on this strategy implies that the therapist will create the opportunity in the group to generate discussions on how to deal with the challenges that the illness may place in the household. This can be achieved either by peer-to-peer inputs, sometimes based on relatives' own experience, or by direct advice from the therapists. This strategy was also prominent in the single-family home sessions. By increasing coping skills, the overall relatives' stress level may decrease. As a consequence, relatives' criticism, hostility and emotional overinvolvement towards the patient may also decrease. The decreasing of hostility and criticism can be explained by the regulation of relatives' fight-or-flight response when faced with a stressor (Kunimatsu & Marsee, 2012). On the other hand, the decreasing of emotional overinvolvement may be explained by a more positive appraisal of stress events (Cotton et al., 2013). Our analysis brings further support to the idea that coping skills enhancement should be a key-element in FIP programmes aiming to regulate EE.

The high frequency of coping skills enhancement in this intervention programme is noteworthy. As described in our systematic literature review (Study 1, Chapter 2), despite being classified by authors as a core component of FIP e.g. McFarlane (1991) coping skills enhancement was found only in some studies, namely Bloch et al. (1995) and Tarrier et al. (1988). Based on this evidence, we argued that coping skills

enhancement should be an advanced therapeutic strategy to be delivered later in a stepped-model intervention. In the present analysis we realised that coping skills enhancement could be delivered very early in the intervention programme. For example, in Group B (from session 36 to the end of the programme) of this analysis, it significantly decreased throughout sessions. How can we explain this? The answer seems to lie on the nature of this programme which was mainly EE targeted. A large proportion of these relatives were high EE and in our analysis, coping skills/ advice was almost entirely directed towards high EE relatives. Therefore, we may consider this intervention programme as part of the most advanced level of the stepped-intervention, where we assumed that coping skills enhancement and advice play an important role.

Emotional support was another frequent therapeutic strategy used in the relatives groups. This implies acknowledging relatives' feelings and offering validation. As we highlighted in Chapter 2, there is strong evidence that emotional support is a key-element of FIP (Budd & Hughes, 1997; Cabral & Chaves, 2010; James, 2006; Levy-Frank et al., 2012; Mannion et al., 1997; Stanbridge, 2003). This idea was supported by our analysis. FIP therapeutic setting should be a sanctuary where relatives freely express their emotions and see them validated. FIP are also a healing process, a place where relatives receive warmth and where their concerns are fully understood by others (relatives and therapists). The group sessions are the best opportunity for this process to happen.

The two remaining most used therapeutic strategies in relatives groups were also prominent in the single-family home sessions i.e. dealing with overinvolvement and reframing relatives' views about patients' behaviours. Dealing with overinvolvement is a key-feature of the Leff and collaborators intervention programme. This therapeutic

strategy is focused on a central component of EE (Brown et al., 1962). This strategy is complex because overinvolvement is merged with strong emotional variables, such as the “Catch-22” syndrome, guilt, and the independence – intrusiveness conflict (Berkowitz, Kuipers, Eberlein-Fries, & Leff, 1981). The “Catch-22” syndrome happens when a relative sees no way of balancing personal needs with the fear that acting on them will have awful consequences on the patient. As a result whatever the relative may do he will feel that he did it wrong. Feelings of guilt arise when relatives question themselves about what they have done that might have contributed to the illness. As a result they try to go backwards to repair (undue) something, and inevitably they will conceive their loved ones as young people, overprotecting them. As a result, relatives will have difficulties in letting patients live independently and separating themselves from their loved ones.

Transposed into practice, dealing with overinvolvement includes: (1) diminishing relative’s guilt; (2) repeating that relatives cannot cause schizophrenia; (3) finding a lever, such as identifying opportunities to improve the patient’s autonomy; (4) to draw relative’s attention to the “When I am Gone” scenario; (5) the collapsed time technique; (6) exploring anxieties about separation; (7) getting relatives to face the impossibility of maintaining constant vigilance; (8) encouraging the two parents to go out together; (9) giving relatives “permission” to relax and enjoy themselves; and (10) encouraging relatives to resuscitate contacts with friends and relations outside the home.

The reframing of relatives’ views about patients’ behaviour, prevailed in both relatives groups and home sessions, is also considered of great importance in programmes aiming to focus on EE. As demonstrated in Chapter 2, there is strong evidence that reframing is a mediating variable in lowering EE (Barrowclough &

Hooley, 2003; Bentsen et al., 1997; Bentsen, Notland, Boye, et al., 1998; Breitborde et al., 2009). Reframing was achieved by cognitive therapy inspired techniques, such as peripheral questioning. It also may be prompted by information, sometimes provided by other relatives, and reality testing. In this analysis we identified some role-plays being carried out by therapists and participants to give relatives a different point of view about their attributions towards patients' behaviours.

3.5.2 What Was the Usefulness of the Different Therapeutic Strategies Throughout the Intervention Programme?

There is no doubt in considering needs addressment a key-element of FIP. This compels effective FIP programmes to be flexible, in contrast with very structured scripts. As we saw in our analysis, therapists must create group moments for relatives to express their needs and share their experiences, almost in every session. This is especially true in the beginning of the programme, as seen with Group B. This strategy is generally accompanied by emotional support and coping skills enhancement. When therapists dedicate some moments to needs addressment and sharing, they have to bear in mind that immediately after they should provide emotional support and coping skills enhancement. FIP should give relatives direct answers, not forgetting the validation component. This could be the start for the individual change process. Again we have to notice this approach contrasts with more structured and non-individual focused programmes.

Sometimes in the beginning of groups it was necessary to introduce strategies to improve group dynamics such as encouraging participants to talk to each other and not to the therapists, and asking participants not to talk all at once. Therapists need to

balance their efforts to give relatives the opportunity to express themselves, in order to regulate communication and progressively direct the content of the sessions to the discussion of themes that are decisive for positive outcome (enhancement of coping skills, dealing with overinvolvement and reframing).

As mentioned above, there was a tendency for dealing with overinvolvement to diminish in Group B, and a tendency for reframing to increase in Group A. With this evidence, it is possible to establish an order of appearance of strategies in the group. First, therapists start with needs assessment and sharing, immediately followed by emotional support and coping skills and advice. The next element to be introduced should be dealing with overinvolvement, and later on reframing. It is noteworthy that single-family home sessions may be introduced in the first third of the programme to augment group related work, namely with these two strategies.

Our analysis also revealed that a substantial part of therapeutic work, at the middle and end phases of each group, was dedicated to dealing with anger, conflict and rejection. It comprises: (1) asking relatives to specify what is it that they are so cross about; (2) showing how a constructive resolution to genuine differences of opinion can be reached out; (3) looking at the positive aspects that still exists; and (4) setting limits. Using this strategy was associated with more emphasis on reframing strategies. Maybe they jointly contribute to lowering criticism and hostility.

It must be recognised that by elaborating on the usefulness of each strategy, we found some odd elements in our analysis. We were surprised by the low use of problem-solving, modelling and working with grief. Problem-solving was identified by some FIP approaches as a key-element (Falloon et al., 1984; McFarlane, 2002), and modelling was a precondition of the model by Leff and collaborators (Kuipers et al., 2002).

Likewise, working with grief has also grabbed the attention of FIP authors (Bentsen, Notland, Munkvold, et al., 1998; Kuipers et al., 2002; Riley et al., 2011). The lack of presence of these strategies in the sessions we analysed, can be explained by the nature of these categories. Despite being specific enough, they are linked with other therapeutic strategies. That is, working with other strategies could also impact on these variables. For example, when low EE participants were spontaneously sharing their caregiving experience they were also modelling high EE relatives. However, as we defined in our code structure, modelling will only be coded when therapists intentionally gave voice to low EE participants to influence others. The same happened with problem-solving, coded only when structured six step problem-solving was applied. Regarding grief work, we found a possible overlap between emotional support or other emotional categories and this category. We only coded work with grief, when this was the only or the predominant feeling. However, it was very often difficult for us to isolate only one emotion, as frequently multiple feelings were displayed. For example, a relative might exhibited anger, and the underlying emotion was grief.

A final comment on the education component. Our analysis revealed a frequency of this strategy in the beginning of the groups, especially in Group B. Education was not associated with any other variables, and it was almost overshadowed by other strategies. We know that all relatives received an individual educational session outside the group. However, we have to note the lack of relevance this component had in these subsequent sessions. If we remember that we were analysing a FIP based on the “psychoeducation paradigm” it is worth noticing the secondary role of education.

3.5.3 Are There Any Differences Between Strategies Used With High EE Relatives and Those Used With Low EE Relatives?

The most obvious differences on the use of therapeutic strategies between low and high EE relatives concerned the amount of intervention they received. High EE relatives received substantially more therapeutic strategies as compared with low EE. Again, this might be related with the level of intervention concerning this programme. In the stepped-model we speculated that not every relative will need advanced strategies. Low EE relatives may not need an in-depth intervention, and hence, it might be difficult to maintain them in the group. This might cause some problems considering the intention to have low EE relatives modelling their high EE peers. However, as mentioned, modelling might be a secondary element of the intervention and therapeutic aims can be achieved through other strategies.

Another difference between low and high EE relatives, was the higher use of therapeutic alliance strategies with low EE relatives. These low EE relatives also received a considerable amount of emotional support. In our analysis establishing a therapeutic alliance involved the offer of positive experiences of contact and informal contacts outside the sessions. This is another fact that may be explained by the stepped-model of intervention. There is some evidence that therapeutic alliance focused interventions produce positive outcomes in the course of the illness (Levy-Frank et al., 2011). We believe that low EE relatives may benefit with low intensity through therapeutic alliance and emotional support, which would correspond to the basic level of the stepped-model of intervention.

The variability of relatives within groups, particularly in Group A, showed that it is possible to have different levels of intervention in the same group i.e. low intensity

common therapeutic factors strategies for one kind of relatives and high intensity coping skills and dealing with EE factors strategies for another set of relatives. However, it seemed to be difficult to keep low EE relatives in the group for long periods.

3.5.4 Final Comments

To our knowledge this was the first comprehensive qualitative study of an effective FIP clinical trial to produce in depth data. Despite having a manual describing the intervention (Kuipers et al., 2002), this study was the first opportunity to empirically evaluate what happened in the process of this intervention.

Even after almost forty years since the original clinical trial, this study is still relevant to produce strong evidence. EE proved to be universal across cultures and over time (Butzlaff & Hooley, 1998). The materials we analysed were unique and of high value because they uncover what happened in the process of an highly effective treatment approach.

The findings we presented were based on a single FIP approach (i.e. the model of Leff and collaborators). In the future, it would be helpful to replicate this study with other treatment approaches, such as Multifamily Group Therapy (McFarlane, 2002), and compare data to understand comprehensively the process of FIP.

CHAPTER 4

A NARRATIVE EVALUATION OF AN EFFECTIVE FAMILY INTERVENTION FOR SCHIZOPHRENIA: THE PERSPECTIVE OF AN OUTSIDE OBSERVER

Study 3

A meeting was held quite far from Earth.

*“It’s time again for another birth” said the angels
to the lord above.*

“This special child will need much love.

*He may not run or laugh or play, his though
may seem quite far away.*

In many ways he won’t adapt, and he’ll be known as handicapped.

So let’s be careful where he’s sent.

We want his life to be content.

Please, Lord, find parents who will do a very special job for you.

*They will not realise right away
the leading role they’re asked to play.*

But with this child sent from above come stronger forth and richer love.

Participant X

*(This poem was written by Participant X and was recited by other participant in one of
the group sessions of the family intervention)*

The knowledge about the process of FIP needs to be extended as a basis to improve their practical application (Cohen et al., 2008; Leff, 2000; McFarlane et al., 2003; Sin & Norman, 2013). The largest effect on relapse prevention ever found was observed in the first clinical trial developed by Julian Leff and collaborators (Leff et al., 1982; Leff et al., 1985; Pitschel-Walz et al., 2001). Therefore, relevance should be placed in analysing in depth what happened in this intervention.

This treatment model was developed in the Medical Research Council's Social Psychiatry Unit in London in the 1970's after the discovery of the influence of EE on the course of the illness (Brown et al., 1962; Kuipers et al., 2002). It was based on pragmatic strategies to diminish EE and to reduce face-to-face contact between patients and high EE relatives. A curious fact is that the authors never had a single label for this intervention. Several terms can be found when referring to this approach: "social intervention", "family work", "combined method" or the "Maudsley approach". The original intervention was based on a mixture of approaches, in different settings. The programme started with a meeting between the professionals and the family, usually at home, where information about the illness was offered. This was also the opportunity to discuss main concerns about the daily life and the recovery of the patient. Following this meeting relatives were invited to participate in relatives groups oriented by two therapists. In addition, some families could receive single-family home sessions during the programme.

In the following sections we will describe the conceptual framework of the FIP developed by Leff and collaborators. We will also narrate the process of the intervention

based on a qualitative analysis of the original records from the first clinical trial of this team. This information will be discussed and contextualised with meetings we had previously conducted with the lead therapists in the trial.

4.1 BASIC ASSUMPTIONS OF THE INTERVENTION MODEL

The intervention model developed by Leff and collaborators may be considered under the umbrella term of “family psychoeducation”. However we have to be cautious with this classification, because the approach had some particularities. It has a psychoeducational component but also deviates from traditional education because it integrates Cognitive-Behavioural Therapy techniques, among other contributions. The assumptions behind the model ratify that: (1) schizophrenia has a biological basis that makes the patient sensitive to stress which might contribute to relapse (i.e. stress-vulnerability model); (2) relatives do not play a part in the aetiology of the illness; (3) the assumptions of some outdated psychodynamic views (in which schizophrenia would be a result of the disturbance induced by parents in childhood), and the contributions of the first systemic authors (in which the patient was viewed as the result of a disturbed family situation) are not used to conceptualize the problem, and this was a major difference at the time the intervention was designed; (4) the stress and burden from being a relative of a person with schizophrenia is validated by the professionals; (5) families are seen as partners in the treatment and professionals share their knowledge about the illness with the caregivers; (6) there should be a relationship of collaboration with relatives resulting in mutual work and setting common goals; (7) relatives do not cause schizophrenia but may have a role in the course of the illness by controlling the

level of stress the patient is exposed, namely the “emotional temperature” in the family environment; (8) families have needs and strengths, and the intervention should be directed in a positive manner to build up these strengths; (9) the family intervention should be delivered alongside optimum pharmacotherapy and other psychosocial treatments; and (10) rapport and therapeutic alliance strategies, such as empathy, are necessary for the intervention, although not sufficient for a good therapeutic outcome.

4.2 MAIN STRATEGIES OF THE INTERVENTION MODEL

Leff and collaborators developed two editions of a book explaining in depth the intervention (Kuipers et al., 2002; Kuipers, Leff, & Lam, 1992). This manual underlies three important issues: (1) the background and basic constructs of the intervention; (2) practical strategies such as engagement, task setting, education and improving communication; and (3) dealing with emotional aspects related with the caregiving role. In Appendix 3 a list of the strategies identified in the manual is presented.

This intervention was intended to work directly on the negative components of EE that are associated with the poor outcome of the patients (i.e. criticism, hostility and emotional overinvolvement). After the engagement phase, task setting, according goals, education and sharing, the programme evolves to more complex and advanced therapy work. In this later phase the strategies are oriented to: (1) improve communication; (2) coping skills enhancement; (3) cognitive reframing about patients’ problematic behaviours; (4) dealing with emotional overinvolvement; (5) dealing with emotional upset; (6) dealing with anger, conflict and rejection; and (6) work on grief.

There are some interesting features in this model that deserve further commentaries. It is expected that therapists assume different roles, from offering positive experiences of contact to direct advice. The therapists should conduct the group in a positive manner, promoting dialogue between participants. This is an important part of the intervention. The participants are encouraged to talk to each other and not for the therapists. The essential role of the therapists is to create an atmosphere in the group that will validate participants, facilitate support, and allow sharing, education, coping skills and direct advice.

4.3 METHODS OF THE NARRATIVE EVALUATION

We conducted a narrative evaluation of the intervention records of the 85 relatives groups' sessions and the 25 single-family home sessions including the patients. This was the same material analysed in Study 2 and described in Chapter 3. These records were synthesis of the sessions including direct speech transcriptions of the most relevant parts. The records also include comments by the therapists about their initial goals and their overall clinical impressions about the course of the session.

We decided to conduct the narrative analysis because of the limitations of the mechanical approach used in Study 2. We aimed to provide an analytical point of view of the observer without predefined categories, allowing for an exploration without borders. Therefore, with the narrative evaluation, the work developed in Study 2 was completed with the observer's inductive reasoning by conveying his perceptions about the records (Bradley et al., 2007).

The narrative analysis was performed alongside and at the same time of the independent coding of Study 2 made by the author. After reading and coding each session for Study 2, we secondarily analysed the records, using the NVivo® version 10 software (QSR International), into two categories: (1) markers of change; and (3) emotional markers. We also wrote general comments quoting our impressions about what happened in the session, namely some reflections about (1) the strategies used by the therapists; (2) group dynamics; (3) the progress of the participants during sessions; and (4) any other important occurrences that would allow information about the process of the intervention. The records were later revised and this material was analysed in depth using again the NVivo® (QSR International). The most relevant moments of the intervention, namely those that were coded into markers, were synthesized. This synthesis was written in a form of a narrative that was later discussed in conjunction with information captured in November 2011, during meetings between the author and some of the therapists that conducted the intervention sessions, namely Julian Leff, Elizabeth Kuipers and Ruth Berkowitz.

4.4 THE NARRATIVE EVALUATION

Relatives Groups

The intervention programme started on the 25th of August 1977. Four participants were attending the first relatives group session. These participants completed the first part of the programme, as others joined the group later. Appendix 1 shows summary information about relatives and their attendances.

The first session started with a brief presentation of participants. As we will see throughout the group sessions, every time a new member came to the group, all participants presented themselves and talked about their caring experiences. In this particular session there were no difficulties for participants to engage and they spent most of the time knowing each other and sharing common difficulties. In this first session, it was very difficult to focus the group on one topic at a time. Therapists had to introduce techniques aiming to improve structure in the group dynamics, namely not to interrupt others and to speak to each other. As mentioned above, a key-feature of this programme was the intention of the therapists to promote dialogues between participants, instead of discussions or top-down explanations delivered by the therapists. In this particular case, therapists had to ask very often for participants to talk to each other and not for them. This was especially observed with Participant 1 (P1). This woman had raised several questions about the causes of schizophrenia, namely if it was hereditary. Others also raised questions on how to cope with delusions and disruptive behaviour. The questions endorsed by the participants were not left without an answer and brief explanations were done. However we noted that therapists were cautious not to assume an educator role and they strategically left these questions to be discussed in the next sessions.

On Session 2, P1 again strongly raised questions about the causes of schizophrenia. P1 was a high EE mother and the therapists realised that her need for reassurance was probably linked with the difficult family situation in her son's childhood. Apparently, the real question beneath the need for information was the sense of guilt this lady felt. Therapists opted not to elicit overtly this feeling. Time was dedicated to discuss the topic of aetiology and it was explicit how the illness was

invariably settled in different family situations. All participants shared their view, and it was possible to observe that the majority of them already acknowledged the stress-vulnerability model. On this session, the therapists started to highlight the comments of P3, a low EE mother that was very keen in sharing and giving advices. Whilst P1 and P2 (P1's husband) were very active in the group, others such as P4, stayed quiet for long periods. Eventually P4 shared with the group his intention to dropout. He pointed out that he was having problems in explaining to his wife (the patient) what the group was all about. To deal with this, therapists proposed a single-family meeting between the psychiatrist, P4 and his wife, to discuss the purpose and usefulness of the group (this individual session will be described bellow).

On Session 3, the group progressed with participants sharing information. Additionally, tips of education about causes and treatment of schizophrenia were advanced by the therapists interchangeably with participants' contributions. Therapists felt the need to interrupt reminiscences about the caregiving experience and the course of the illness. This was an obstacle to discuss current ways of coping with patients' problematic behaviours (e.g. drinking), which was a need elicited by themselves. Some relatives, especially the high EE ones (P1, P2 and P4), were just raising questions and were not giving the opportunity for the group to discuss ways of coping. They always fell back into reminiscences. Therapists dealt with this assuming a directive role and conducting the group to focus on current problems and sharing alternatives of coping. This was successfully achieved and the group started to be more organised and focused. In sum, before the intervention of the therapists, relatives were expressing needs but were unable to focus on processes that would allow themselves to be opened and to create an internal personal space capable of generating psychological transformations,

and thus, fulfil their needs. We interpreted this difficulty, especially shown with high EE participants, because of the intensity of their feelings of anger and despair. After being validated on the first sessions, and after having the opportunity to share these feelings with the group, they were now opened to move to new “psychological ground” when trying to find new ways of coping with the illness. The role of the therapists was essential to promote this space by organising and prompting dialogues.

From Session 4 onwards, the group became more structured and participants started to give emotional support to each other. The emotions of the participants in the group were changing from anger to a calmer register. However, they seem sadder and sometimes hopeless. Even the low EE relative, P3, had shared some worries with others and received extended support from P1. It was interesting to see this change of role of P1. In the beginning she almost overshadowed the others, and now she looks calmer and focused, giving support to P3. From Session 6 to 10, participants discussed orderly their problems and gave support and advice to each other. P1 and P2 were having problems with their son’s drinking and lack of activity. Other participants reported the same problem and the therapists prompted the group to explore how to cope with this. Special attention was dedicated to the lack of interest patients’ had in comprising daily activities. By this time (sessions 6, 7 and 8), P1 and P2 were very sceptical about a suggestion made by the doctors encouraging their son to left home and stay in a hostel. The group discussed the issue of independence. P3 made very good suggestions on diminishing the involvement of relatives when they try to impose routines in their loved ones. She suggested that they should go “half-way” and must be cautious on expecting too much from their loved ones. She also suggested, with the help of the therapists, that relatives should trust in patients’ independence.

Meanwhile, two new members (P5 and P6) joined the group. Time was dedicated for them to be introduced and tell their narratives. P5 only attended a few sessions as she moved with her husband to another town. Hereafter, P6 was the focus of attention from the group. It was possible that previous members realised how comforting it was for them to have space to express their concerns in the first sessions. Now they were doing the same with the new members. The atmosphere was quite positive and empathic. The group found different ways to deal with unexpected situations and started to explore how a solution to their problems would look like. By this time, the group was working in an atmosphere of humour with liveliness and concern about genuine problems. However, when exploring patients' behaviours, there was still the tendency to interpret patients' attitudes in the "all or nothing" rule: either violent or ill, either restrained or without control.

Meanwhile, P1 and P2 were having problems with their son as he returned home after leaving the hostel by himself with the protection of his mother. There was some despair in the couple, but on the other hand, the feelings of anger were now less pervasive. Time was again dedicated to discuss the worries of P1 about her son's independence. The therapists again prompted dialogues aiming to diminish preoccupation about patients' independence

On Session 11, P4 dropped out. He had expected to participate only on a previously agreed number of sessions and decided to quit. In his final session he found out that his attitude, of first restraining feelings and then to overreact, was certainly not helping him to cope with his wife. While he was leaving the group it was possible for him to gain some insight regarding his behaviour and this was very rewarding for him and the rest of the group.

From sessions 10 to 15, participants were concerned about the problems of each other by asking questions and making suggestions. There were no difficulties about raising sensitive issues. The group focussed on patients' aggressive behaviours and the difficulty in dealing with the feelings that such behaviours evoked. Again, particular attention was paid to P6. This woman was overwhelmed by her husband's (patient) aggressiveness and received lot of support from the group. P1 was especially sensitive to this issue and for the second time changed her role in the group. On the first sessions she almost self-centred the dialogues and now she was quite focused on giving support to others and to discuss orderly the problems raised in the sessions. The group discussed obstacles in the families which hindered the patients to become a full family member again. The dialogues between participants were very rich and resulted in normalizing experiences of living with a person with schizophrenia.

On session 12, P1 and P2 reported a change in attitudes towards their son. They mentioned an episode when they let him to go out with his friends without worrying too much. However, on session 14, the couple strongly disagreed with each other regarding their views about how their son experienced a visit from an old girlfriend. This moment generated an opportunity to discuss openly their disagreement and to show their current difficulties. With the help of the group, they normalized the conflict, pointing out the positive sides that still existed in the family. They could ask for solutions, instead of complaining individually. They were able to stay calm while disagreeing and move forward to generate constructive alternatives. This constructive attitude was seen in the forthcoming sessions as the couple continued to present specific problems without "defences".

Session 17 was dominated by two recent crises: P1 and P2 were having trouble with their son's drinking and his subsequent rebellion behaviour; and P6 had had a particularly bad week with her husband's disorganized behaviour which eventually resulted in a readmission to the hospital. The group explored what happened and tried to understand all the different dimensions of these difficult episodes.

From sessions 15 to 19, the group went to explore the reasons underneath patients' problematic behaviours. This work resulted in the reframing of relatives' expectations about patients' behaviours and subsequently the uselessness of their overinvolvement. This was clearly demonstrated by exploring the attitudes of the son of P1 and P2 that continued to drink while staying at home with the protectiveness of his parents. By this time, there was some intensification of advice from the group and the therapists encouraged P1, P2 and P6 to become less involved. In the case of P1 and P2, it was identified a lever for this purpose. A girl who was staying at home as a guest, to whom their son was also a friend, was identified by the group and the therapists to be a good influence on the boy. The group suggested that maybe she could encourage him to get out more often. The contribution of low EE relatives was determinant in helping P1 and P2 to consider the possibility of "letting go" their son without too much worries. P1 said something completely impossible to hear in the first sessions. She stated that she was now thinking that it was more productive not to control his son's life. On the next sessions it was possible to observe significant markers of change in the couple. They started to be more positive and gave themselves time to relax.

Session 20 was marked with a new occurrence. P6's husband asked her for divorce. The next sessions were dedicated to her concerns. She had the opportunity to express her feelings of anger followed by sadness and despair. A great help came from P7, a low EE man who was dealing wisely with his spouse. P7 identified himself with P6, as he also had had a similar experience one year before, when his wife asked him for divorce. He validated P6's feelings and reframed her view by pointing out that probably this was an impulsive idea and her husband would back off. The therapists reinforced this belief by stating that probably this proposal from her husband was meaning that he wanted some reaction from her.

Later on, P6 made some changes. She wore a new hairstyle and stayed more relaxed and less sensible to her husband's disruptive behaviour. The group was very successful in building P6's self-esteem. She received support and positive feedback that helped her to reframe and to point out the positive sides that still existed in her life.

On session 27, P9 joined the group. Again, a relative that was highly critic and omnipresent became less extreme (this had already happened with P1 when P6 arrived to the group). This time it was P6 that became less critical by identifying herself with the narrative of P9. By this time it was also possible to observe that low EE relatives, especially P3, were very important in supporting and helping high EE relatives to reframe their views about patients' behaviours. This was so namely in attributing behaviours, such as the lack of initiative and social withdrawal, to the illness rather than to bad intentions of their loved ones. These contributions of low EE patients were either spontaneous or prompted by the therapists by asking them to analyse thoroughly those behaviours.

On session 29, it was very interesting to observe another marker of change in P6. She had gone to a party and her husband said he would paint the bedroom. On other occasions, she would have difficulty in going out and letting him to do such task alone. But on this occasion she had bought the paint and he did paint the room. This successful episode was highly reinforced by the group and it seemed that others also benefited from this achievement as they showed their willing to do the same with their loved ones.

From sessions 30 to 35, the group progressed with fewer attendances with some sessions having only two or three participants. During this period, sessions only made a boost of previous contents. By this time, P9 was the rookie of the group and benefited from the help of P7 (low EE). P7 repeated what he did with P6 i.e. he had identified himself with the difficulties of P9 and suggested new ways of interpreting and coping with her husband's behaviour. Later on, P9 said that she learnt from the group to have different expectations from her husband and now she was more tolerant with him.

On session 36, all group members except P9 were newcomers. After 18 months since the first group session, a great proportion of the participants felt they had fulfilled their needs of intervention. This could be an indicator of the optimum treatment duration. The total mean of attendances of the first 35 sessions was 11 sessions. If we exclude two outliers, that only participated in one session (P8 and P10), the mean number of participations was 14. We should note that the three most dramatic high EE participants (P1, P2 and P6) were especially assiduous. These three participants, out of ten, were responsible for 54% of the total of the attendances in the group.

On the next nine sessions the group had low levels of attendance with some sessions only having two participants. Only three persons came interchangeably to these sessions. Once again, in this initial phase of the group, the role of the therapists was concentrated on encouraging detailed dialogues about current problems and not reminiscent narratives. By this time there were no low EE relatives in the group. However the arrivals of P11 and P12 had a great impact on P9. Again the effect of passing the role to new members was observed. This may be called a “Relay Effect”. In fact, there was a tendency for high EE relatives, who were having most of the attention from the group, to pass their positions to newcomers with equal extreme narratives, and thus, changing the role from receiving support and advice, to being themselves the sources of support and advice. Therefore, we observed that former participants started to lower their emotionality in the group when new members arrived. On this occasion the phenomenon was observed with P9, passing the “relay baton” to P11 and P12.

P11 had a dramatic situation at home. Her daughter heard “voices” and had paranoid thoughts about her maternal half-brother. The “emotional temperature” at home was very high and hostile. As a result, P11 intensified her protectiveness towards the ill daughter and had to deal with the pressure of her son. Paradoxically, on other occasions she was very critical and hostile with her daughter.

The other new member, P12, had a difficult situation with her husband which was unemployed and absent of daily routines at home. She did not accept this situation.

After a couple of sessions, with the group sharing structured narratives and receiving support by each other and the therapists, P11 and P12 started to show

markers of change. Therapists asked for clear elaborations about current problems and not reminiscences. Discussions started to be focused on how to cope with the lack of activity of the patients. The group started to be more focused and placed the anger aside. Eventually, P11 withdrew to talk with her daughter all night to calm her down about her worries, and now she was giving direct instructions for her to go to the bed. Similarly, P12 told the group that she felt less worried about the future, partly because she felt she was more aware of what was going on with her husband and now she could have different expectations about his capabilities. These two women influenced each other in a positive way by reframing their views about patient's behaviours.

On the next meetings until session 45, while speaking about current difficulties, group members shared episodes where they had lowered their emotional involvement towards patients. They also started to display new expectations from the patients in the family, namely by having their personal space and being autonomous. P11 thought her daughter could start to care of her grandson and to do some housework.

P11 endorsed by self-recreation a curious reality testing. One night she made an odd test pretending that she was ill. As a result her daughter cooked the dinner for the first time since a long period. This episode generated humour in the group and reinforced the possibility to involve patients in daily routines without great stress. Likewise, P12 also started to give her husband a role of responsibility and equality. She started to share her thoughts about the need for him to get a job, even a less rewarding one, rather than protecting him.

The views of P11 and P12 about the illness and the capabilities of the patients substantially changed. From one hand, they understood the difficulties that patients with schizophrenia might have in dealing with former routines and roles. On the other hand, they now believe in their autonomy and prompted patients to assume attainable goals consistent with their new roles in the family. This change in beliefs contributed for sure to lower their EE.

The achievements of P11 and P12 were remarkable, and curiously they only attended eight and thirteen sessions respectively, for about ten months. These were considerable fewer attendances as compared with P1, P2, P6 and P9. Another important fact was that they did not have the influence of low EE relatives, because low EE relatives were not attending the group by this time. However, the therapists could manage dialogues towards acceptance, and the influence of P9, which was going down in her EE was important. Another difference of the participations of P11 and P12, as compared with previous participations, was the low level of attendances on the sessions they had participated: during the sessions they were attending the group had only two or three participants.

On sessions 45 and 46, the group received new participants. Again some sessions were dedicated for participants to know each other and to share their narratives. With this group in particular this phase took longer than usual because the group was receiving new elements almost every session. By this time, the “therapeutic chorus” slowed down and there were not significant changes in the participants.

On session 54, P14 broke down into tears because of the feelings of rejection by her son. This emotional disclosure was a lever for the group to react

and move to new psychological ground. Others gave extended support and tried to reframe her views about the attitudes of her son, by pointing out that withdrawal does not mean rejection but is rather a symptom of the disease and that their loved ones also lack of conversation at home. These dialogues were prompted by the therapists and generated straightforward explorations related to this topic. P14's husband (P15) was also attending the group sessions. The couple (P14 and P15) seemed less worried after this session and started to accept the negative symptoms of schizophrenia by identifying social withdrawal as a result of the illness.

On session 56, all present participants were relatives with high EE. This had already happened from sessions 36 to 45, but these participants had entered the group very recently and the group was crowded, making it difficult to focus on therapeutic work. When therapists guided the group to explore different perspectives or alternative coping behaviours they were seldom successful. An all-or-nothing cognitive distortion was observed in almost every participant. This was especially intense with P13, a woman facing rage outbursts from her son and generally reacting with criticism. Her behavioural repertoire when faced with the verbal aggression of her son was very limited, mainly consisting of a passive-aggressive attitude. On session 57, the therapists invited P13 to participate in a role-play. One therapist was pretending the role of P13, and P13 was pretending her son. The role-play simulated an argument between both mother and son. All participants were invited to share how they felt during the exercise. P13 said that she felt "terribly negative, dull and wretched", and suddenly, realised that this was what her son felt. She also found that the therapist was overtly hostile and critic, and afterwards, she admitted that sometimes her behaviour was just like that. This

behavioural exercise was confrontative of P13 behaviour. However, the final result was positive. On the next session, P13 looked calmer and seemed able to face the more painful aspects of her son's illness. She became more empathic and started to listen to her son. This achievement spread through the group and from then on there were fewer difficulties in generating alternative repertoire.

On session 59, P14 stated an interesting aspect. She said that at that time she was always telling herself "we can't protect them all the time". She also started to use the word "acceptance" very often. P13 reinforced this movement by talking about her new attitude. She has decided on a new strategy with her son since the previous meeting. She started to spend time sewing in her own room, and when the environment was tense, she avoided the kitchen so that she keeps out of her son's way and "avoid a scene". The previous sessions had been an opportunity for participants to realise that some annoying behaviours of their loved ones were caused by the illness, and that patients need a comfortable space to achieve their autonomy.

Session 62 was entirely dedicated to appreciate the gains in patients' behaviours. This was an opportunity to reinforce the new attitudes of the relatives by relating these gains to their new strategies.

The following sessions were dedicated to P18's problems. Her daughter was very possessive of mother's attentions, constantly asking her to interpret social episodes (e.g. what people thought about her). P18 had been overprotecting and somehow permissive. On this subject, it was interesting to observe P14 giving direct advice to P18, encouraging her to become less involved with her daughter's affairs. She gave several direct examples of how she had coped leaving her son

alone more often and having time to herself. On session 63, P18's husband (i.e. P20) was invited to participate in the group. This strategic invitation was made the therapists who had in their mind that P20 was low EE. It was interesting to observe the tendency of P18 to interrupt her husband when he was starting to speak in the group. The therapists and the group reinforced what P20 was trying to say on lowering contact with their daughter and on becoming less involved. The group and the therapists encouraged the couple to give themselves a treat and they both agreed to go away to see P20's new grandson.

On session 65, P18 said that her daughter had been disruptive and complaining about the lack of attention from her. P18 was unsure of what to do. The group encouraged her to stay firm and reframed positively the situation by stating that this could be viewed as the beginning of the autonomy of the girl. The therapists took up this optimistic note and related the patient's reaction against her mother to a teenage rebellion which marks the beginning of growing up and autonomy from getting away from parents.

By this time, the participation of P9 is noteworthy. She was in the group from session 27 to session 86, comprised three years of participation and 41 sessions. This high level of attendances raised some interesting issues. During the first sessions, she received plenty of support and advice from the group. She was the centre of the attentions. Afterwards, she inverted the role with new members as described in the "Relay Effect". From then onwards, the participations in the group were mainly to give support to other participants and model positive attitudes. She almost "made the job" of low EE relatives. As an example, on session 68, she described a very enjoyable trip with his husband, highlighting the benefits of

programming pleasure activities within the family. These positive contributions were of great value as they spread out and modelled positive emotions and behaviours in other participants.

On the last 14 sessions of this clinical trial, the group discussions were focused on three newcomers (P19, P21 and P22). Eventually, P21 received the highest level of attention. P21 was very hostile and critical towards her daughter. She spent the first sessions in the group expressing anger and despair with her situation. As opposed to what had been usual, where participants tended to be very supportive to each other, this time the group reacted with some confrontation against P21 complains. This was especially true with P13, who was sometimes aggressive towards P21, perhaps because P21's daughter was doing relatively well. She worked in Bethlem Hospital as a typist and did not have significant disruptive behaviours. She only had some bizarre behaviour and was withdrawn and stubborn. To deal with this conflict, therapists invited three participants (including P13 and P21) to role-play a situation between P21 and her daughter. P21 did not gain insight about her reactions instantly, however on the next sessions she was calmer. She started to receive support from the group and others could challenge her attributions towards her daughter's behaviour. As usual, the therapists prompted dialogues between participants to explore patients' attitudes, analysing first their impact in the family, moving to the exploration of the causes of these behaviours (i.e. attributing them as a result of the illness) and finally focusing on new ways to cope. Afterwards, P21 started to understand her daughter better.

From sessions 76 to 80, therapists were highly committed to elicit change speech in P21 and other participants. The discussions of P21 problems were

opportunities for others to think about their own situations. The therapists were frequently asking for alternative interpretations about the situations.

On session 81, P21 definitely became less rigid and showed that she could let go the control over her daughter. Her speech changed from being questioning and critical all the time (with emotional overinvolvement), to become focused on facing the real situation. Emotionally she shifted from anger to sadness. After being comfortable about expressing her feelings of grief in the group, she started a process of cognitive reattribution and as a result she changed her attitude. Curiously, this was very similar to what happened with P1 in the beginning of the treatment programme.

The last group meeting took place on the 25th February 1982. The group ended in a highly positive atmosphere with participants maintaining positive and informal contacts between each other and the therapists.

Single-Family Home Sessions

The first single-family home session took place on the 13th October 1977 at the home of P4 and his wife (the patient). The atmosphere was quite positive. The therapists assessed the progressions made by the patient and there was lot of optimism. She was attending a course of book-keeping and learning to sew at night. P4 was taking her to these classes but she returned home by herself. After some group sessions, P4 was relying more on her autonomy. The therapists took this opportunity to reinforce what was going on, stressed the need to continue with the same approach and addressed the importance of P4 to keep participating in the relatives group. This was done having in mind the problem raised by P4 in the

group, when he shared his intention to dropout because he was having difficulties telling his wife about the purpose of the sessions (as described above).

The next home meeting was at P1 and P2's home. As opposed to other single-family home sessions the patient was not present at this meeting. The therapists wanted to see P1 and P2 separately as a couple, and how they were coping since their son left home going to a hostel. In the group sessions, P1 showed difficulties in allowing independence of her son. P2 was less rigid. The therapists spent some time trying to understand in depth the motives behind P1 overinvolvement. The therapists noted that she worried about the capability of her son to take care of himself. They discussed these difficulties and endorsed the importance for him to become independent as it was expected at this phase of the life cycle. The worries of P1 were cleared up. If something bad happened he will receive help from the service. P1 asked the therapists about the causes of the illness (as she did on the first sessions of relatives groups). The therapists spent some time offering education about this topic.

This home meeting was very productive because it allowed an open discussion of P1's worries about the independence of her son. She was less keen to do it in the group sessions and the home meeting was decisive for this disclosure. Another meeting was offered if it was necessary and eventually four months later a second home session was undertaken after their son returned home (again without his presence). The aim of this session was to ensure that their son would return to the hostel. Again, time was spent to listen to P1's worries and the content of the previous session was boosted. The problem of drinking was particularly focused because this was one of the major concerns of P1. On this session, it was possible

to observe a split between the couple as P2 was already less involved and keen to let the patient to go on independent. It was agreed that the couple would continue to attend the group and that these topics would be discussed there.

P6 also received one home session together with her husband (the patient). The session was dedicated to both express their views about the current situation. It was possible to observe some criticism of P6 towards her husband's silence. She did not realise that this was the meaning of his general lack of interest (related with the disease) and not a rebuttal of her ideas. The therapists decided to introduce positive feelings in the conversation and asked the patient about the aspects he liked on his wife. The atmosphere turned positive and both participants were asked to develop a plan to avoid circular reactions of hostility whenever the patient got tense. It was agreed that at these times he should be alone and avoid contact with his family until he got calmer.

The home session with P11's family was an opportunity to understand the origin of "the voices" of her daughter and to agree on alternative coping mechanisms. This was a very calm meeting without conflicts and both participants were solution focused to cope with their difficulties. This was also the opportunity to agree that during the night they both should be in their bedrooms and not talking about the "the voices" (auditory hallucinations) or other issues. This suggestion resembled what was said before during the group sessions. Again, therapists emphasised the importance of the participation of P11 in the group sessions and it was cleared up with her daughter what the group was all about.

After four months, there was another home session with P11 and her daughter. Despite the alert made by the registrar after a contact with the patient,

nothing relevant had happened and the session was only a booster of the previous meeting. Again, the theme of coping with “the voices” was raised, as well as the need to diminish contact between mother and daughter. Time was also dedicated to find out the possibility of the patient to start new activities such as reading.

The first home session dedicated to P13 and her family started in a heavy atmosphere. P13’s husband was being highly critical towards his son. The therapists validated his frustration and afterwards turned his attentions to explore the motives behind his son’s lack of activity. The patient was given a voice to explain himself. Everybody had the opportunity to express their own ideas and it was agreed that he would undertake some activity. P13’s husband asked for permission to talk with the therapists without his son. The boy pacifically left the room and the father pointed out his worries about the future, namely if he and his wife would not be able to live their retirement with quality (e.g. travelling abroad). This was an opportunity to encourage the couple to become less involved with their son.

Three months later there was a second meeting with this family. Again, P13’s husband was very critical towards his son and therapists needed to deal with anger and rejection by asking the father to imagine what was going on with his son.

On a third meeting, only with mother and son (the father was absent), the therapists were faced with the persistence of conflicts between family members. They focused on communication skills training, helping the patient to express his emotions directly to his mother. The problem was that, at that time, this family only showed two possible mood states: no emotion or violence. This all-or-nothing atmosphere was maintained by almost every family member, and P13 was suffering

because she was the “family temperature thermostat”. This was discussed and more adequate coping strategies were agreed.

The team also arranged a few home sessions with P17 and her family. However, on the first planned session only P17 was at home. The therapists discussed further ways for her daughter to become more independent, but P17 raised an issue. She was afraid that her daughter would run away with some man, which already happened twice in the past before she got ill. However, P17 agreed on trying some changes, namely that she would at least let her daughter sleep in her own bed.

On a second meeting, father and daughter were also attending. This time therapists were faced with a “communication chaos”, everyone speaking at the same time. After some prompts by the therapists it was possible to focus the family on current problems such as the parents’ worry that her daughter would go out at night to dance and meet with men. It was agreed that if the daughter wanted to have independence from her parents, she had to give reasons for parents to trust her.

Two more sessions were offered to this family. On the third session, again the topic of patient’s responsibility was raised. It was stressed by the therapists that it was very important for the patient to manage her money correctly, to sleep in her own bedroom and to go to the day centre. The fourth session resembled these advices and the family emotional environment was calmer. The attitude of the therapists prompting the family to problem-solving and facilitating agreements seemed to be decisive for a good outcome.

The largest number of single-family home sessions of the trial under analysis was offered to P18. Overall, she had seven home sessions, the same

number of her attendances in the group sessions. On the first session with P18 and her daughter, therapists gave the opportunity to both to express their current difficulties and worries. Their speech was validated and the therapists raised the need for the patient to be occupied.

On the second session, it was possible to openly discuss the benefits of introducing some separation between mother and daughter. This topic was raised again on the third home session, this time with the presence of P18's husband. This low EE relative was crucial in helping to relieve the worries about separation. On the next session, the therapists (by knowing that P18 had had a difficult childhood after the death of her mother), tried to establish some links between this and her need to protect her daughter. They had hoped that by acknowledging this fact, P18 could become less involved. However, they did not succeed.

On the last two home meetings with this family, the therapists changed the strategy by focusing on giving direct advice to the patient on how to manage individually her symptoms. This would make her less dependent on the mother because her tendency was to talk with her every time she was uncomfortable.

The last home session with this family took place six months after the first meeting. The session was scheduled after a call from the patient asking the therapists to come. They were presented with a very good surprise. Despite some P18's overinvolvement was still present, the family looked calmer and relaxed. The patient was very pleased to tell the therapists her new coping mechanisms to deal with "the voices" (auditory hallucinations). Even humour was possible to introduce when P18 said that she could never stop from being alert and hearing what was happening with her daughter. In a comfortable atmosphere the therapists joked

saying that if she put earplugs it would help with this kind of voices. Everybody laughed. This was a signal that the family was now recognizing and accepting the symptoms of the illness and managed to cope with them.

The last three single-family home sessions of this clinical trial were dedicated to P21's family. During the meeting with P21 and her daughter (the patient) the therapists were faced with a very hostile situation. P21 was being very critical, blaming her daughter for not "doing nothing" at home. The level of conflict was so high that therapists decided to retry for while to find out what to do with this situation. They decided to clearly advice P21 not to expect her daughter to do nothing, simply because she was not able to do what was expected from her at that time. They pointed this several times. Despite realising that P21 was not accepting the idea, therapists decided to be assertive. P21 was furious with them when they left the house.

On the second session with this family, therapists started to ask the patient for things that she could manage to do as expected by her mother. They all agreed that she would start to wash the bath after using it. P21 was only asked to prompt a small sentence in case her daughter forgot to do what was agreed. The attitude of P21 was always very confrontative and the focus of the therapists was to encourage the patient to go to a day centre and to rely on group sessions for a change on P21.

4.5 DISCUSSION

We performed a narrative evaluation of the intervention records of one of the most effective FIP clinical trials (Leff et al., 1982; Leff et al., 1985). This analysis was

made alongside a mechanical qualitative approach used in Study 2, and intended to illustrate the course of the intervention and to explore the most important therapeutic moments. It relied on the opinion of an external observer of the process reflecting upon the therapeutic strategies, group dynamics, emotional markers and markers of change in the participants. This study had a wider range of analysis, by using an inductive approach, thus being more vulnerable to observer bias, as compared with Study 2.

In the present study (Study 3) it was possible to focus on the individuals and to identify some patterns of change in the participants. Change markers were also associated with emotional changes, as participants expressed different feelings throughout the group sessions.

As described in Chapter 2 (Study 1), the importance of the common therapeutic factors is considerable in FIP. This analysis suggested additional evidence supporting this. The first sessions of the relatives groups were dedicated to building therapeutic alliances and rapport between the group members, and between them and the therapists. As the programme developed, every time a new member came to the group, time was dedicated to participants to know each other. To produce an empathic environment it was usual to have long periods in the sessions (sometimes entire sessions) for participants to share their inner feelings and current difficulties. The group usually generated empathy and participants gave support to each other, as well as therapists did. The curious aspect that we called “The Relay Effect” was clearly a demonstration of how participants were considering the problems of others. The group atmosphere was friendly and positive in general, and sometimes it was even possible to introduce humour. Besides empathy, support, positive regard and positive experiences of contact, the great availability of the therapists to attend participants’ needs is noteworthy. This

was also demonstrated in the single-family home sessions. When therapists were leaving the meeting they invariably said that they could come back for another session if it was necessary. In fact, one of the therapists stated during one meeting with the author that the perception of the participants of having someone who cares about their difficulties was very important for positive outcome. A curious demonstration of this was the reported annoyance of a mother when she stopped receiving letters from the therapists inviting her to the meetings, even though she had never attended the group.

The focus on common therapeutic factors in the initial phase was extremely important and therapists continued the sessions always underlining this dimension. However, after the introductory sessions it was necessary to direct participants to discussing current problems. On some occasions this was very difficult to achieve. Participants had the tendency to persist in giving detailed reminiscences of the evolution of the illness and telling about the most disturbing moments they had. As one of the therapists suggested in another meeting with the author, these reminiscences were generally accompanied by feelings of anger related with non-acceptance of the illness. This state was most frequent with high EE relatives. They tended to see the illness as a threat to their integrity as persons, like if they had done something wrong. Therefore, beneath the feelings of anger it was frequent to find feelings of guilt. This combination was particularly found in P1, P14, P18 and P21. When participants moved from reminiscences to focus on current problems, a move which was generally prompted by the therapists, they regulated their feelings of anger and could calm down, staying more neutral. However, after addressing current difficulties, feelings of loss and anguish tended to arise. We saw this happening very often in the group sessions. As a result, after exploring patients' behaviours and facing the current impact of the illness on daily

life, participants had to receive extended support from the group and the therapists. The lesson learned from this evidence was that one should only prompt participants to concentrate on current difficulties after they are well engaged in the group. After doing such move, the group and the therapists must be prepared to give further support to those participants as they will face feelings of loss, anguish and despair. Nonetheless, sometimes anger may appear interchangeably with these emotions, and therefore therapists must be concentrated on emotional markers at this part of the programme.

The next task developed throughout the group sessions was focused on exploring the reasons why patients were behaving in a certain way. The therapists encouraged participants to analyse the reasons underneath patients' attitudes by sharing ideas as a group. This strategy seemed to be nuclear in the intervention, as it absorbed a great portion of time in the group sessions. These explorations were also filled with information giving. Education was either shared between participants or delivered by the therapists. This allowed relatives to understand that other patients had similar problems to those of their loved ones (a normalization effect). The overall result of this process was generally the reattribution of patients' behaviours. Frequently in the group we found a relief by the relatives when understanding that disruptive or withdrawal behaviours were related with the illness. In fact, one of the therapists told the author about the importance of the cognitive change of the attributions of relatives towards patients' behaviours. This fact is related with the evidence by Breitborde et al. (2009), which found that high EE relatives tend to perceive the expression of symptoms as stemming from patient's agency more frequently than low EE relatives. As described in Chapter 2, studies about mediator variables that were included in our systematic

literature review point out that this change is essential in diminishing EE, particularly criticism and emotional overinvolvement and hostility to some extent.

When the group explored what lied beneath patients' behaviours, it was also usual to discuss coping skills to deal with those behaviours. Coping skills enhancement was frequently one of the primary goals of the therapists, as shown by their notes when planning the sessions. The improvement of the sense of control over situations was also an important contribution to achieve a positive outcome in regulating EE. By improving their coping repertoire, relatives calmed down and their sense of despair lowered.

We should also emphasise the work on diminishing overinvolvement. On this subject, it was frequent to observe direct advices from therapists and other participants encouraging the independence of patients, and the need for relatives not to exercise much control over the life of their loved ones. Sometimes therapists recurred to role-plays, giving the opportunity for relatives to experience and gain insight on how involved with their loved ones' affairs they were, and how easy it was for them to exasperate and start to be hostile.

Another important aspects worth to explore were the circumstances and the number of attendances of P11 and P12. They only attended ten sessions approximately and however made remarkable changes. By that time, there were no low EE relatives attending the treatment programme and sessions had few attendances (sometimes only two participants). This may suggest that in some cases small groups are more efficacious than large groups. Additionally, the effect of low EE participants may be replaced by the contributions of former high EE participants, which are lowering their EE and may positively influence newcomers.

A final comment on the relevance of the single-family home sessions. As mentioned above, all families had education sessions (not available for our analysis) before their inclusion in the programme, and many of the discussions that took place in the relatives groups, namely when exploring the motives beneath patients' behaviours, benefited from the information they had acquired. This facilitated relatives to understand what was going on with their loved ones.

The single-family home sessions that we analysed were scheduled while participants were attending the group. As described above, home meetings were opportunities for the families to describe difficulties with current problematic behaviours and to agree on alternative coping mechanisms, and for therapists to advise on decreasing contact between patients and relatives, whenever adequate. Therefore, home meetings were enhancers of the group work. Additionally they allowed therapists to improve the commitment of patients in the process and to give them some advice about recovery (e.g. go into a day centre). Finally we should emphasise the practical contribution of these single-family sessions as they were an opportunity to augment the engagement of relatives with the group sessions and to clarify, together with the patients, what the group was all about, and therefore demystifying their concerns about this subject.

CHAPTER 5

OVERALL COMMENTS AND CONCLUSIONS

Fortunately there is the style. Do you wonder what it is? Consider that style may be a subtle way of transfer, by a mental plan, the completion and violence of life to a unit of meaning. Do I make myself clear? No? Well, we cannot stand the disarray of life.

So we grab it and separate it into two or three interrelated topics that equate... I resolved thousands of equations... After listening to Bach, I got a style. I apply it at night, when I wake up at four a.m. It's simple, when I wake terrified, watching the great shadows rising up in the middle of the room, when the light is at your fingertips, and all the world seems to go up with the blood and shadows' dark voices...

Then I start making my style.

Herberto Helder (Portuguese poet)

in Os Passos em Volta

(free translation)

5.1 OVERALL COMMENTS

The three studies described in this thesis assigned new evidence to understand the process of FIP. The need to identify the key-elements of the process of FIP has been mentioned during the last two decades. However, little research has been done.

Our research produced in-depth data and to our knowledge it was the first of its kind. Previously, the knowledge about the process of FIP was largely based on experts' opinions and consensus. We aimed to move a step forward by increasing at least one level of evidence on this subject i.e. from experts' opinions to comprehensive qualitative research (Peterson et al., 2014; Taylor & Hignett, 2014). Studies 1 and 2 were conducted under the best known practice rules of validity and reliability of qualitative research. Data were rigorously analysed and methods were designed to achieve powerful results. Study 3 allowed a wider view about the process of the intervention without *a priori* constraints.

However, some limitations are to be acknowledged:

- (1) In Study 1, it was not possible to clearly identify the outcome of all interventions. For example we were not able to distinguish between studies focusing on clinical and functioning outcomes, and those mainly addressing caregivers' burden. Sometimes this information was not clear in the articles. Likewise, because we were interested in gathering the maximum possible number of studies, we decided not to restrict our search to studies where the efficacy of the intervention was known. Similarly, it was not possible to control relatives' variables, such as level of distress or EE, because this information was absent or limited in the studies we reviewed;

- (2) The records analysed in Studies 2 and 3 were highly relevant and unique. They contained accurate descriptions of the most relevant moments in the sessions with direct speech transcriptions and descriptive clinical comments of therapists that became experts in field recognised worldwide. However, they were not exhaustive transcriptions of the entire content of the sessions. Therefore it is possible that some important content might be missing;
- (3) The records were written material and as a result it was not possible to evaluate speech utterance and pitch. When we coded emotional markers on Study 3, we based our decisions on the content of the speech and on the clinical comments and descriptions of the therapists;
- (4) Study 3 was a narrative evaluation of an outside observer relying on an inductive qualitative approach. The observer bias should be taken in consideration when elaborating on the conclusions of the study;
- (5) Study 2 was not able to analyse the process of transformation of individuals throughout the intervention programme. Despite we made some considerations in Study 3 about markers of change in the individuals, our data were not suitable to evaluate with high accuracy the process of change in individuals (that should be a question for other study with different type of data). Our focus of analysis was on the process of the intervention rather than on the individual transformations;
- (6) Studies 2 and 3 were based on the Leff and collaborators FIP approach. Therefore we have to be cautious in generalising its conclusions to other FIP approaches with methodological differences.

5.2 OVERALL CONCLUSIONS

Throughout this research project the information regarding the process of FIP was increasing and a structure was gaining consistency. Figure 25 provides a graphical longitudinal view describing our major findings regarding the process of the FIP programme under analysis. This evidence is consistent with the major ideas presented in the intervention manual which was based on the opinions of the authors about the programme (Kuipers et al., 2002). The work undertaken in the relatives groups may be strengthened by including a few single-family home sessions in the programme.

By synthesising our findings we reached the following overall conclusions.

Overall Conclusion Number 1

FIP are one of the most effective psychosocial treatments on relapse prevention. The inclusion of FIP together with treatment as usual, could have the same relevance in the treatment of psychosis, as compared with the effects of new developments in pharmacological treatment. However, practical application of FIP has been demanding. The lack of knowledge about the process of FIP might have been an impending factor on this subject.

There is a gap on qualitative research about the process of FIP. Before we have initiated our work, there was only one study comprehensively exploring the process of an effective FIP approach (Bloch et al., 1995). However it revealed only scanty conclusions.

Overall Conclusion Number 2

Common therapeutic factors may be key-elements of FIP. So far these factors were mainly seen as facilitators in the engagement process. The evidence we reviewed suggested that for some relatives this could be enough to achieve positive outcomes with impact on patients' clinical state.

We propose a stepped model of intervention with different levels of strategies being delivered to relatives, starting from interventions focused on the common therapeutic factors, moving to education, then to coping skills and further ahead, strategies aiming to work directly on EE.

Overall Conclusion Number 3

The most relevant therapeutic strategies of the Leff and collaborators FIP are in order of prominence: (1) the dedication of time to create therapeutic moments where relatives share their needs and concerns with the group; (2) enhancement of coping skills and advice on how to deal with the difficulties placed by the illness; (3) emotional support; (4) dealing with overinvolvement; and (5) reframing relatives views about patients' behaviours. The first three therapeutic strategies seem to be positively associated. When the first occur, the other two increase their likelihood to occur as well.

Overall Conclusion Number 4

Strategies aiming to deal with overinvolvement may occur very early in the treatment programme (when relatives with high EE are included).

Overall Conclusion Number 5

Dealing with anger, conflict and rejection are better suited to occur in the middle and in the end of the programme. This work should be combined with reframing strategies. We believe that this combination is effective in lowering criticism and hostility.

Overall Conclusion Number 6

Single-family home sessions including the patient, might be useful to reinforce the work being done in relatives groups, namely to deal with overinvolvement. However, these sessions might not be necessary if relatives are motivated to attend regularly to group sessions.

Overall Conclusion Number 7

The process of the FIP model of Leff and collaborators embraces emotional changes in the participants. In our analysis we unveiled that on the first sessions, high EE relatives tend to express their feelings of anger with some intensity. Therefore, therapists have to make efforts in directing participants to face current problems and interrupt reminiscences. In the following therapeutic moments, participants may start to experience loss and anguish. As a consequence, therapists must create conditions in the group that will allow relatives to receive emotional support, and then conveying strategies aiming to improve their ability to deal effectively with the illness. This work should be done in a way that participants could reach positive appraisal of stress situations by reframing their views, so that positive feelings such as acceptance, positive regard, and the sense of control and security, could start to rise.

Overall Conclusion Number 8

FIP programmes with high EE relatives should include advanced strategies (e.g. dealing with overinvolvement; reframing; dealing with anger/ conflict/ rejection) and should be conducted by experienced therapists with knowledge and experience about processes of change.

Overall Conclusion Number 9

Therapists must conduct the group conveying opportunities for participants to positively influence each other. This can be achieved through the inclusion of low EE relatives in the same group, or with the influence of older participants on newcomers (The Relay Effect). For this purpose open groups are better than closed groups.

Overall Conclusion Number 10

Low EE relatives benefit with therapeutic alliance and emotional support oriented strategies. Other therapeutic strategies seem to be less relevant with low EE relatives.

5.3 THE NEW DEVELOPMENTS AND THE PSYCHOEDUCATION PARADIGM

The term “psychoeducation” was adapted to family interventions trying to overcome the barriers of implementation (i.e. helping relatives to accept the intervention). Invariably, this designation called the attention to the education component. Therefore, education has been the front image of FIP. We acknowledge that

education is an important component of FIP. However, it is only one important component in the middle of others. As we demonstrated, there are other key-elements that seemed of greater relevance. This finding was consistent with previous evidence and opinions arguing in favour of the less relevance of education on FIP (Dixon et al., 2001; Goldstein & Miklowitz, 1995; Lam, 1991). Therefore, calling “psychoeducation” to a complex intervention such as FIP can be considered a misnomer. Besides, there are risks in using this nomenclature. In practical application, clinicians may turn their attentions to the education component forgetting the other key-elements. As a result, people may receive packages of intervention that do not resemble the real elements that make FIP effective. We believe that the term “family psychoeducation” should progressively substituted by the term “family interventions”. The most important guidelines (e.g. NICE and PORT Recommendations) already use this nomenclature. Efforts must be made to generalise.

5.4 FUTURE DIRECTIONS

In this research we made three pioneer studies providing strong empirical information about the process of FIP. We hope that this work will bring further enthusiasm around FIP. Our project should be replicated, and new qualitative studies evaluating the process of FIP should be conducted in short-term, namely qualitative research alongside randomised controlled trials of other treatment approaches. These results should be compared with our findings.

FIP are complex interventions with an array of different strategies, including those that are also used in approaches such as the Cognitive-Behavioural Therapies

(Kuipers, 2006) and the Systemic Family Therapies (von Sydow, Beher, Schweitzer, & Retzlaff, 2010). For example, some strategies to deal with overinvolvement are very similar to those used in systemic approaches (Gonçalves-Pereira, 2010). Therefore, attempts should be made to develop bridges between these approaches and FIP in order to improve the knowledge about the mechanisms of action beneath some therapeutic strategies of FIP.

With this research project we accumulated evidence to the state of the art about the process of FIP. It is now possible to affirm that the common therapeutic factors, needs addressment, sharing, coping skills, advice, emotional support, dealing with overinvolvement, reframing and education, are key-elements of FIP, especially on interventions aiming to regulate EE. Other strategies could also be secondarily incorporated. In the future, experimental studies with complex intervention designs (Craig et al., 2013), controlling for participants and strategies variables, should compare the effect of each one of these key-elements, and observe their individual contribution to the overall efficacy of FIP. With these contributions, the paradigm of FIP may hopefully evolve in the near future.

Figure 25

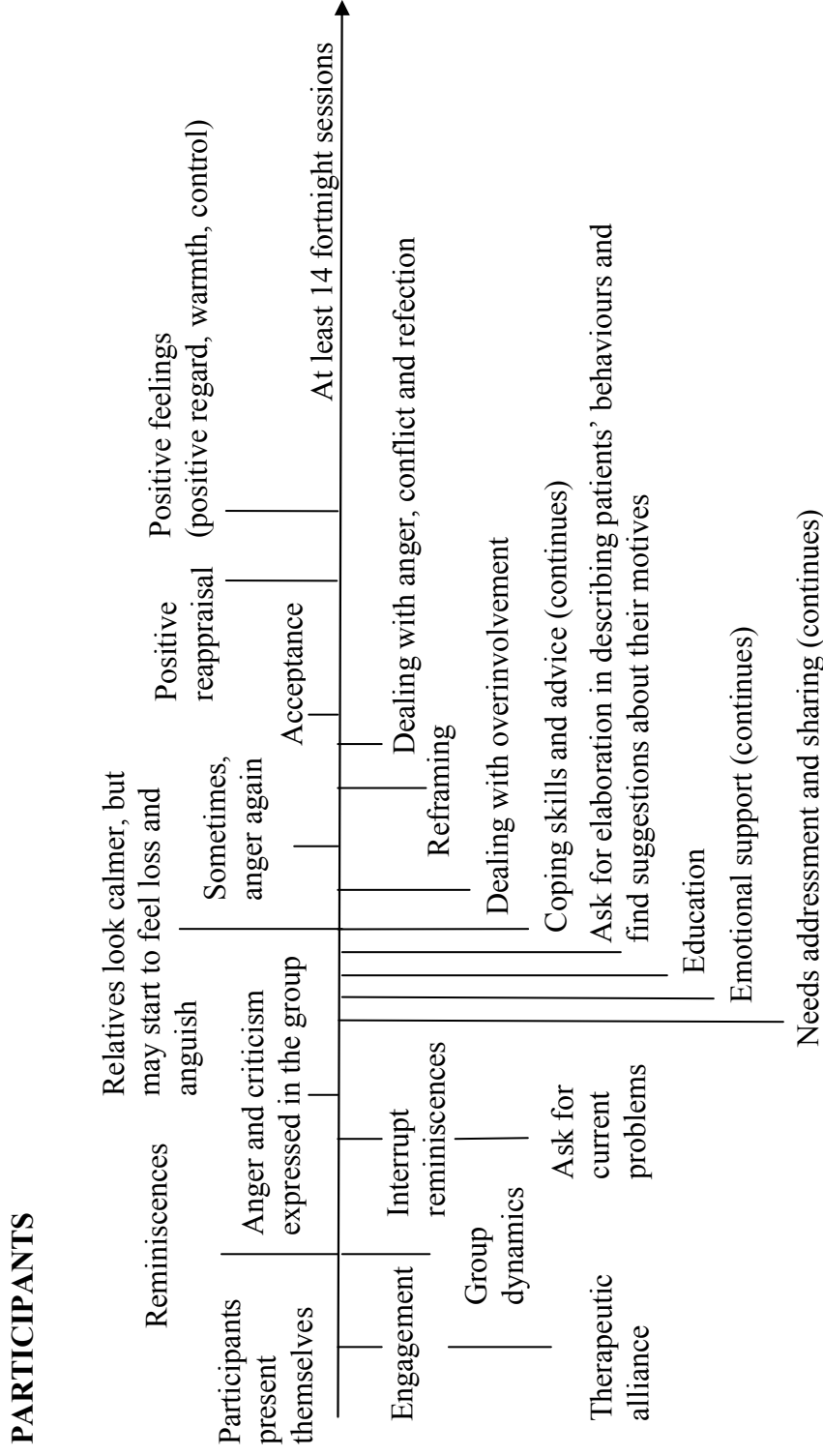


Figure 25. Longitudinal view of the major findings regarding the process of the Leff and collaborators FIP approach.

OVERVIEW IN PORTUGUESE (RESUMO ALARGADO)

As perturbações psicóticas são doenças mentais complexas sendo influenciadas na sua etiologia e prognóstico por factores biológicos e psicossociais. A interferência do ambiente familiar na evolução da doença espelha bem esta realidade. Quando em 1962 George Brown e colaboradores descobriram que ambientes familiares com elevada Emoção Expressa (EE) contribuíam para um aumento significativo do número de recaídas de pessoas com esquizofrenia (Brown et al., 1962), estava aberto o caminho para o desenvolvimento de novas intervenções familiares. A EE inclui cinco componentes: três componentes negativos, i.e. criticismo, hostilidade e envolvimento emocional excessivo; e dois componentes positivos, i.e. afectividade e apreço (Amaresha & Venkatasubramanian, 2012; Kuipers et al., 2002).

No final dos anos 1970 surgiram os primeiros trabalhos na área das intervenções familiares nas psicoses (IFP). Dois grupos em países diferentes, no Reino Unido e nos Estados Unidos da América, desenvolveram quase em simultâneo duas abordagens distintas. Em Londres, a equipa liderada por Julian Leff desenhava uma intervenção combinando sessões unifamiliares em casa, incluindo o paciente, e sessões em grupo, apenas para os familiares (Leff et al., 1982). Por seu turno, em Pittsburgh, Gerard Hogarty e colaboradores desenvolviam uma abordagem que compreendia a dinamização de sessões educativas em grupo (Anderson e tal., 1980). Para designar este trabalho, Hogarty e colaboradores propuseram o termo “psicoeducação”. As IFP começaram a ser conhecidas por esta designação que se generalizou até aos dias de hoje. Neste contexto a educação era vista como a partilha de informação acerca da doença, dos profissionais para os familiares. Nas sessões os profissionais eram

informados acerca das manifestações, etiologia, tratamento e evolução das psicoses, bem como de formas para lidar com as situações difíceis geradas pela doença, e.g. risco de recaída.

Os trabalhos pioneiros das IFP foram rapidamente sucedidos pelo desenvolvimento de novos modelos e a proliferação de estudos de eficácia. Para além dos modelos de Leff e Hogarty, os modelos IFP que ficaram mais conhecidos foram: (1) a Terapia Familiar-Comportamental, desenvolvida por Ian Falloon e colaboradores (Falloon et al., 1984); e (2) a Terapia Multifamiliar em Grupo, desenvolvida por William McFarlane e colaboradores (McFarlane, 1991).

O incremento de estudos de eficácia contribuiu rapidamente para as primeiras meta-análises. Estas, por sua vez, resultaram na inclusão das IFP nas normas de orientação clínica mais relevantes para o tratamento das psicoses, nomeadamente da esquizofrenia (e.g. PORT Recommendations e NICE Guidelines). No geral os estudos apontavam para uma diminuição do risco de recaída na esquizofrenia na ordem dos 20 a 50% em dois anos (Pitschel-Walz et al., 2001). No final dos anos 1990 as IFP atingiam assim o apogeu. Contudo, a sua aplicação prática tem ficado aquém do esperado e as barreiras à implementação das IFP passaram a ser o foco das atenções (Gonçalves-Pereira et al., 2006; Leff, 2000). Simultaneamente, alguns autores começaram a levantar a questão da incerteza sobre quais os elementos-chave da intervenção. O conhecimento sobre o processo das IFP era reduzido e começaram a surgir as primeiras publicações sobre o assunto (Lam, 1991). Em 1997 foi dinamizada uma reunião de consenso entre os três investigadores mais relevantes do momento, Falloon, Leff e McFarlane. Deste encontro promovido pela World Schizophrenia

Fellowship for Schizophrenia and Allied Disorders surgiu um documento estabelecendo dois objectivos e quinze princípios para as IFP (WFSAD, 1997).

Não obstante os contributos que foram feitos, continua a existir uma grande falta de evidência empírica acerca do processo das IFP e dos seus elementos-chave (Cohen et al., 2008; Dixon et al., 2001; Lam, 1991; Leff, 2000; McFarlane et al., 2003). Também em Portugal, apesar da reflexão teórica nesta área e do registo de ensaios de efectividade de grupos para familiares – estudo FAPS (Gonçalves-Pereira, 2010), os componentes fundamentais das IFP nunca foram analisados directamente.

Assim, o projecto de investigação descrito nesta tese teve como objectivo identificar os elementos-chave das IFP com base em investigação qualitativa. Para tal, conduzimos três estudos que nos permitiriam alcançar dados empíricos sobre o tema.

*O **primeiro estudo** (descrito no Capítulo 2) consistiu na realização de uma revisão sistemática da literatura científica acerca das variáveis relacionadas com o processo das IFP. A nossa pesquisa esteve focada essencialmente em estudos qualitativos. Contudo, decidimos não restringir demasiado os critérios de inclusão tendo em conta as dificuldades em pesquisar sobre investigação qualitativa nas bases de dados electrónicas e também devido ao facto de ser possível obter informação sobre as variáveis relacionadas com o processo a partir de estudos quantitativos. O método para este estudo foi baseado no PRISMA Statement para revisões sistemáticas da literatura. Depois de definirmos os critérios de inclusão e exclusão, iniciámos várias pesquisas nas bases de dados electrónicas utilizando termos booleanos, trunicações e marcadores de campo. Pesquisámos na PubMed/MEDLINE, Web of Science e nas bases de dados incluídas na EBSCO Host (Academic Search Complete; Education Research Complete; Education Source; ERIC; and PsycINFO). As pesquisas geraram*

733 resultados. Depois de serem removidos os duplicados, 663 registos foram analisados e foram seleccionados 38 artigos em texto integral. No final, 22 artigos foram incluídos na síntese qualitativa tendo sido agrupados em quatro categorias: (1) estudos examinando de forma abrangente o processo; (2) estudos acerca da opinião dos participantes sobre a intervenção que receberam; (3) estudos comparativos que individualizaram variáveis sobre o processo; e (4) estudos acerca de variáveis mediadoras.

Os resultados evidenciaram um considerável hiato na investigação em torno do processo das IFP. Identificámos apenas um estudo que abordava de forma abrangente o processo das IFP (Bloch, et al., 1995). Este artigo descrevia uma análise qualitativa de um estudo experimental de uma IFP. Contudo, as suas conclusões gerais revelaram-se pobres e apenas se podia extrair com certeza de que as IFP devem ser baseadas nas necessidades dos participantes e que os terapeutas devem assumir diferentes papéis ao longo da intervenção.

Da revisão foi possível perceber que os factores terapêuticos comuns como a aliança terapêutica, empatia, apreço e a “aceitação incondicional”, podiam ser eles próprios um elemento isolado para a eficácia das IFP. Outros estudos enfatizaram a educação como elemento chave da intervenção (e.g. Levy-Frank et al., 2011), ao passo que outros ainda colocavam a ênfase no treino de estratégias para lidar com a doença i.e. coping (e.g. Tarrier et al., 1988). Com base nesta diversidade de resultados e tendo em conta algumas propostas prévias de peritos (McFarlane, 1991; Liberman & Liberman, 2003), desenvolvemos a hipótese de concebermos as IFP como um processo por etapas, de acordo com as necessidades dos familiares. No primeiro nível estariam as estratégias relacionadas com os factores terapêuticos comuns e o suporte emocional,

no segundo nível a educação acerca da doença, e num nível mais avançado, o foco seria o treino de estratégias para lidar com a doença e diminuir a EE. Neste estudo concluímos que nem todas as famílias iriam precisar de IFP complexas e que nesses casos seria possível obter resultados favoráveis com IFP pouco intensas.

*O **Estudo 2** (descrito no Capítulo 3) consistiu numa análise qualitativa dos registos clínicos do primeiro ensaio clínico da IFP de Leff e colaboradores (Leff et al., 1982). Este ensaio clínico culminou numa das evidências mais substanciais alguma vez alcançada com uma IFP (Leff et al., 1982; Leff et al., 1985; Pitschel-Walz et al., 2001). Este estudo teve como objectivo modular a EE recorrendo a um modelo misto com que compreendia sessões familiares em grupo e algumas sessões unifamiliares em casa, incluindo o paciente. Os resultados mostraram uma diminuição das recaídas em nove meses de 50% no grupo de controlo para 8% no grupo experimental.*

Os registos analisados neste estudo datam do período de 1977 a 1982 e podem ser considerados como material histórico de alto valor, que surpreendentemente nunca tinha sido analisado. Eram compostos por descrições pormenorizadas dos terapeutas, incluindo excertos em discurso directo e estavam descritos segundo uma estrutura, contendo também os comentários dos terapeutas. No total os registos representavam 85 sessões em grupo para familiares durante os cinco anos do ensaio clínico e 25 sessões unifamiliares em casa incluindo o paciente. Para a análise qualitativa decidimos utilizar um método de análise dedutivo, com uma abordagem mecânica de codificação dos registos em categorias previamente definidas. Tomámos esta decisão com base na extensão apreciável dos registos e porque tínhamos disponível informação válida acerca das categorias que iríamos encontrar nos mesmos, nomeadamente a informação contida no manual da intervenção, publicado sob a forma de livro, e nos resultados da

nossa revisão sistemática da literatura (Estudo 1). Deste modo, foi construída uma grelha com a estrutura de codificação, que serviu de base para a análise, envolvendo 15 categorias.

De modo a cumprir com critérios de validade e fidelidade rigorosos, optámos por executar uma dupla codificação independente. Deste modo dois observadores leram e codificaram independentemente os registos. As discrepâncias na codificação foram revistas até se obter um consenso. No caso de não ser possível chegar a acordo, um terceiro observador, mais experiente nos aspectos técnicos das IFP, tomaria a decisão sobre a codificação. A análise foi executada com recurso ao programa informático NVivo® versão 10 (QSR International). O número de vezes que cada estratégia foi utilizada foi contabilizado, especificando a sessão e o participante. Os dados foram depois exportados para uma base de dados e analisados recorrendo ao programa informático de análise estatística SPSS® versão 20 (IBM Corp.). Foram realizadas explorações estatísticas para descrever os dados e obter informação sobre possíveis relações entre as variáveis. De modo a perceber a significância das observações, recorreremos a testes de hipóteses, utilizando as equações de estimação generalizadas.

Os resultados da análise revelaram que as estratégias terapêuticas mais utilizadas na intervenção em grupo foram: (1) a criação de momentos para ouvir as necessidades dos participantes e para a partilha de preocupações entre eles – representando 21% de todas as estratégias utilizadas; (2) treino e aconselhamento acerca de formas para lidar com os aspectos mais difíceis da doença – 15%; (3) criar condições para que os participantes recebam suporte emocional – 12%; (4) lidar com o envolvimento emocional excessivo 10%; e (5) o reenquadramento das atribuições dos

familiares acerca dos comportamentos dos pacientes – 10%. Nas sessões unifamiliares em casa, as estratégias mais utilizadas foram: (1) lidar com o envolvimento emocional excessivo – representando 33% de todas as estratégias utilizadas nas sessões unifamiliares em casa; (2) treino e aconselhamento acerca de formas para lidar com os aspectos desafiadores da doença – 22%; e (3) o reenquadramento das atribuições dos familiares acerca dos comportamentos dos pacientes, juntamente com o lidar com a zanga, o conflito e a rejeição – ambas com 10%.

A análise longitudinal mostrou que a criação de momentos para ouvir as necessidades dos familiares tende a acontecer invariavelmente ao longo do programa. Sempre que isso acontece, são geralmente utilizadas estratégias para ajudar os familiares a lidarem melhor com os aspectos difíceis da doença e estratégias para fomentar o suporte emocional. Por sua vez, foi possível perceber que o trabalho para diminuir o envolvimento emocional excessivo pode acontecer logo nas primeiras sessões. O reenquadramento e o lidar com a zanga/ conflito/ rejeição tendem a acontecer a partir da fase intermédia até às últimas sessões.

A análise das diferenças entre os familiares com baixa EE e os de elevada EE, mostrou que os familiares com elevada EE tendem a tornar-se o foco da intervenção grupal. Por sua vez, os familiares com baixa EE recebem mais estratégias relacionadas com aliança terapêutica, comparativamente com os familiares com elevada EE.

São de realçar os dados relativamente às estratégias educativas. Foi possível observar que estas tendem a acontecer mais no início dos grupos, não estando associadas a outras estratégias. Contudo é de notar a sua baixa utilização, a rondar apenas os 5%.

O Estudo 3 (descrito no Capítulo 4) surgiu como uma forma de completar a análise do Estudo 2, permitindo uma visão mais narrativa do processo e focando, adicionalmente, as mudanças que ocorrem nos participantes. Com base nos mesmos registos utilizados no Estudo 2, codificámos de forma secundária os registos em duas categorias i.e. marcadores de mudança e marcadores emocionais. Os marcadores de mudança foram cotados sempre que um participante exibia comportamentos ou pensamentos diferentes dos anteriores no sentido de uma eventual redução na EE. Os marcadores emocionais correspondiam à expressão intensa de sentimentos por parte dos participantes nas sessões e que estariam relacionados com assuntos-chave para essas pessoas. Os excertos que continham a informação destes marcadores foram posteriormente revistos e articulados com notas e comentários não estruturados que recolhemos durante a codificação do Estudo 2. Com base nesta informação os registos foram revistos e, utilizando um método indutivo, elaborámos uma narrativa acerca da intervenção. Os resultados da narrativa foram discutidos com dados de que dispúnhamos, referentes a reuniões com os terapeutas envolvidos na intervenção em análise (Elizabeth Kuipers, Ruth Berkowitz e Julian Leff; Londres, Novembro de 2011).

Reconhecemos que, pela sua natureza não estruturada e indutiva, a avaliação narrativa está mais sujeita ao viés de observador. Não obstante, os resultados deste Estudo 3 parecem revestir uma consistência elevada. O mais relevante foi a evidência de que na intervenção em análise ocorreram mudanças emocionais significativas nos familiares ao longo das sessões em grupo. Numa fase inicial os familiares tenderam a expressar sentimentos de zanga. Seguidamente, os terapeutas iam interrompendo o discurso de reminiscências, direccionavam o discurso para as suas preocupações actuais e os familiares pareciam ficar mais calmos. Contudo, à medida que os

participantes “mergulhavam” nos problemas com que se confrontavam na altura, os sentimentos de zanga davam lugar a sentimentos de perda e angústia. Nessa altura os terapeutas enfatizavam o suporte emocional e introduziam progressivamente técnicas de reenquadramento para ajudar os participantes a avaliar de forma mais positiva as situações. Este trabalho dava lugar a sentimentos mais positivos, como a aceitação, apreço e a sensação de controlo.

O Estudo 3 evidenciou também o que designamos como o “Efeito de Passagem de Testemunho”. Este efeito aconteceu sempre que um membro novo se juntava ao grupo. Os membros antigos, que estavam a ser o alvo das atenções e naturalmente a receber mais intervenção, mudam de papel e passam eles próprios a focar as suas atenções nos membros mais recentes do grupo, contribuindo para a dinâmica do grupo com as mesmas intervenções que os ajudaram previamente. Por exemplo, alguns membros antigos que eram altamente críticos nos grupos em relação aos seus familiares passavam a fazer comentários de reenquadramento dirigidos para os novos membros.

Por fim, o Capítulo 5 resume as conclusões gerais deste projecto de investigação. Os estudos apresentados permitiram um incremento no conhecimento acerca do processo das IFP. Anteriormente esta informação era baseada sobretudo na opinião de peritos. Com este projecto aumentámos o nível de evidência ao apresentar estudos com base em dados empíricos. A análise qualitativa do Estudo 2 permitiu pela primeira vez, tanto quanto é do nosso conhecimento, perceber de forma aprofundada o processo subjacente a uma IFP (no contexto de um ensaio clínico que se revelou como um dos mais eficazes de sempre). Identificámos as estratégias mais utilizadas, as relações entre elas e a sua diferente aplicação entre familiares com baixa EE e

familiares com alta EE. O Estudo 3 completou a informação incluindo aspectos relacionados com as mudanças individuais durante o programa. No final foi possível perceber que as IFP devem ser um programa por etapas. Nos Estudos 2 e 3, evidenciámos que numa fase inicial, os terapeutas dedicaram especial atenção para que os familiares tivessem espaço para partilharem as suas necessidades, disponibilizando logo de seguida estratégias para promover o suporte emocional e estratégias de coping. Num nível subsequente do programa, o trabalho terapêutico avançou para estratégias mais direccionadas para regular a EE, mantendo sempre as estratégias iniciais ao longo das sessões. Assim apesar de a educação ter sido um componente importante na IFP em análise, houve outras estratégias mais relevantes no processo.

A evidência gerada pelos Estudos 2 e 3 baseou-se em registos históricos de elevado valor, sendo que os constructos subjacentes na época, nomeadamente a EE, continuam a ser a base da investigação e prática das IFP a nível mundial em diferentes culturas (Butzlaff & Hooley, 1998).

Concluimos que as IFP são um processo complexo com diferentes níveis de intervenção, podendo gerar mudanças emocionais nos participantes durante as sessões. No futuro será importante replicar o nosso trabalho (nomeadamente o Estudo 2) com outras abordagens de IFP, de modo a obter informação acerca do seu processo. Esse conhecimento será fundamental para uma possível evolução do paradigma das IFP.

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APPENDICES

Appendix 1

Description of participants and their attendances

Participant	Level of EE	Relationship	Number of		
			Attendances	First Session	Last Session
P1	High	Son	18	1	25
P2	High	Son	20	1	25
P3	Low	Son	18	1	32
P4	High	Wife	11	1	11
P5	High	Husband	4	6	11
P6	High	Husband	24	7	33
P7	Low	Wife	10	19	34
P8	Low	Son	1	24	24
P9	High	Husband	41	35	85
P10	Unknown	Son	1	35	35
P11	High	Daughter	8	36	46
P12	High	Husband	13	36	54
P13	High	Son	24	45	85
P14	High	Son	30	45	85
P15	High	Son	32	46	85
P16	Low	Daughter	2	47	49
P17	High	Daughter	5	51	60
P18	High	Daughter	7	53	65
P19	High	Son	15	61	83
P20	Low	Daughter	1	63	63
P21	High	Daughter	18	67	85
P22	High	Son	6	67	79

Appendix 2

Code Structure for Study 2

Therapeutic Alliance

Engaging

Offer positive experiences of contact

Informal contacts outside the sessions

Emotional Support

Acknowledgement of relatives' feelings

Validation

Relatives give support to each other

Needs Addressing and Sharing

Asking relatives for their difficulties

Relatives spontaneously share their own difficulties

Setting the aims of the intervention based on relatives' needs

Group Dynamics

Encourage participants to talk to each other and not to the therapists

Asking participants not to talk all at once

Encouraging the reserved participants to speak

Education

1. Tailored: information provided by the therapists tailored to relatives' difficulties

2. General: information provided by the therapists regardless relatives difficulties

3. Shared: participants give information to others based on their own knowledge

Coping Skills and Advice

Direct peer-to-peer or therapists advice on how to deal with patients' problematic behaviour

Problem Solving

Specific problem solving step-by-step techniques

Modelling

Therapists show how they deal with their own difficulties in the group in a positive and constructive manner

Reframing

Reframing relatives' views about patients' behaviour

Dealing With Emotional Upset

Normalising emotional responses

Positive reframing about the situation

Pointing out that there is a positive reason for the intensity of the feeling

Dealing With Overinvolvement

Diminishing relative's guilt

Repeating that relatives cannot cause schizophrenia

Finding a lever

To draw relative's attention to the "when I am gone scenario", The collapsed time technique

Exploring anxieties about separation

Getting relatives to face the impossibility of maintaining constant vigilance

Encouraging the two parents to go out together

Giving to relatives "permission" to relax and enjoy themselves

Encouraging relatives to resuscitate contacts with friends and relations outside the home

Working With Grief

Encouraging relatives to express their feelings of loss, emphasising the positive sides that still exist

Working With The Family's Sense Of Stigma

Information to demystify the illness

To normalise families' feelings

Sharing of feelings, grievances and past experiences with other group members

Encouraging carers to form relationships outside immediate family

Persuading relatives to test their beliefs that people will reject them because of the illness

Getting absent family members involved

Involving the "peripheral" family network for support

Coping with non-attendance

Coping with lack of interest in meetings

Appendix 3

List of therapeutic strategies of the Leff and collaborators FIP

retrieved from Kuipers et al., (2002)

- Therapeutic Alliance
 - Engaging
 - Offer positive experiences of contact
 - Informal contacts outside the sessions
- Setting the aims of the intervention
 - Therapist driven
 - Parental families
 - To encourage cooperation between parents
 - To balance power between parents and patient
 - To strengthen boundaries between parents and patient
 - To release parents from full-time caring
 - Marital families
 - To balance power between partners
 - To enhance couple's enjoyment of the relationship
 - To help adjust roles in the family
 - To ensure that the partner gets some time off from caring
 - Together with the participants/ needs
 - Briefing
 - Parental families
 - To encourage cooperation between parents
 - To balance power between parents and patient
 - To strengthen boundaries between parents and patient
 - To release parents from full-time caring
 - Marital families
 - To balance power between partners
 - To enhance couple's enjoyment of the relationship

- To help adjust roles in the family
 - To ensure that the partner gets some time off from caring
- Debriefing
- Modelling
- Education
- Improving communication
 - Establishing the ground rules
 - Only one person may speak at a time
 - Talk to the person
 - Speaking time should be shared equally
 - Listening skills
 - Preventing talking over and interrupting
 - Active listening training (e.g. asking for paraphrase)
- Task setting/ Problem solving
 - Setting a realistic list of goals
 - To reframe a global criticism to set a goal
 - Setting an agenda and prioritising
 - To give to each family member an opportunity to voice problems and concerns (SS)
 - To instruct to focus only at one problem at a time
 - Negotiating solutions and agreeing on homework
 - To explore each family member's views
 - Checking up on homework
 - Positive reinforcement successes on homework
 - To praise and value any small change
- Dealing with emotional upset
 - Normalising emotional responses
 - Positive reframing
 - Pointing out that there is a positive reason for the intensity of the feeling
 - Seeing family members separately

- To reinforce generational boundaries
 - Cement marital alliances
 - To listen to emotional issues that may upset patient or other family members
 - To engage families who feel that no one has previously listened to them
 - To separate hostile or intractable relatives
 - Looking at areas of mutual concern
 - Role play (role reversal)
- Dealing with anger, conflict and rejection/ Coping
 - Defusing anger
 - To ensure that each family member will be listened to
 - To formalise rules of turn taking and listening
 - Asking relatives to specify what is that they are so cross about
 - Keeping control
 - Clear and firm reminders of why they are meeting
 - Reminding the rules for improving communication
 - Model positive negotiation
 - Showing how a constructive resolution to genuine differences of opinion can be reached out
 - Look at the positive aspects
 - Limit setting
 - Unpacking a violent incident within the family
 - Preventing violence to reoccur
- Dealing with overinvolvement
 - Diminishing relative's guilt
 - Repeating that relatives cannot cause schizophrenia
 - Finding a lever
 - To draw relative's attention to the "when I am gone scenario"
 - The collapsed time technique
 - Exploring anxieties about separation

- Getting relatives to face the impossibility of maintaining constant vigilance
 - Encouraging the two parents to go out together
 - Giving to relatives “permission” to relax and enjoy themselves
 - Encouraging relatives to resuscitate contacts with friends and relations outside the home
 - Encouraging relatives to resume leisure interests
 - Appreciating eventual advantages of letting go overinvolvement
- Replacing the role of carer
 - Congratulate and acknowledge that no one can adequately replace the relatives, but affirming that for the patient to achieve independence the carer had to gradually withdraw from the role
 - Asking carers to remember what activities they enjoyed before and encouraging relatives to resume leisure interests
- Limit setting
 - Encouraging relatives to respect their own needs and sense of comfort
 - Negotiating and agreeing on setting limits for patient’s behaviour and demands
 - Giving patient’s the opportunity to state what limits they would want
- Achieving independence
 - Agreement on small achievable tasks for the patient to tackle
- Strategic moves
 - Change seats
 - Splitting up the family
 - Recounting past separations
 - Paradoxical injunctions
- Working with grief
 - Encouraging relatives to express their feelings of loss (RG or SS)/ sharing

- Emphasising the positive sides that still exist
- Sharing other families' experiences (RG)
- Working with the family's sense of stigma
 - Education to demystify the illness
 - To normalise families' feelings
 - Sharing of feelings, grievances and past experiences with other group members (RG)
 - Encouraging carers to form relationships outside immediate family
 - Persuading relatives to test their beliefs that people will reject them because of the illness
 - Persuading patients to test their beliefs that people will reject them because of the illness (HM)
- Getting absent family members involved
- Involving the "peripheral" family network for support
- Coping with non-attendance
- Coping with lack of interest in the meetings
- Helping marital families
- Group dynamics
 - Encourage participants to talk to each other and not to the therapists;
 - Asking participants not to talk all at once;
 - Encouraging the most reserved participants to speak