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Journal:	BMJ Open
Manuscript ID:	bmjopen-2014-006108
Article Type:	Research
Date Submitted by the Author:	14-Jul-2014
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<b>Primary Subject Heading</b> :	Mental health
Secondary Subject Heading:	Mental health, Communication, Evidence based practice
Keywords:	Schizophrenia & psychotic disorders < PSYCHIATRY, Health policy < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, Organisational development < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, Quality in health care < HEALTH SERVICES ADMINISTRATION & MANAGEMENT

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# TITLE PAGE

'Implementing family involvement in the treatment of patients with psychosis: a systematic review of facilitators and hindering factors'

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#### ABSTRACT

#### **Objective:**

To synthesise the evidence on implementing family involvement in the treatment of patients with psychosis with a focus on barriers, problems and facilitators.

#### Design:

Systematic review of studies evaluating the involvement of families in tripartite communication between health professionals, 'families' (or other unpaid carers) and adult patients, in a single-family context. A theoretical thematic analysis approach and thematic synthesis were used.

#### Data sources:

A systematic electronic search was carried out in seven databases, using database specific search strategies and controlled vocabulary. A secondary hand search of grey literature was performed as well as using forwards and backwards snowballing techniques.

# **Results:**

A total of 43 studies were included. The majority featured qualitative data (n=40), focused solely on staff experiences (n=34) and were carried out in the United Kingdom (n=24). Facilitating training and ongoing supervision needs of staff are necessary but not sufficient conditions for a consistent involvement of families. Organisational cultures and paradigms can work to limit family involvement, and effective implementation appears to operate via a whole team co-ordinated effort, at every level of the organisation, supported by strong leadership. Reservations about family involvement regarding power relations, fear of negative outcomes and the need for an exclusive patient-professional relationship may be explored and addressed through mutually trusting relationships.

#### **Conclusions:**

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Implementing family involvement carries additional challenges beyond those generally associated with translating research to practice. Implementation may require a cultural and organisational shift towards working with families. Family work can only be implemented if this is considered a shared goal of all members of a clinical team and/or mental health service, including the leaders of the organisation. This may imply a change in the ethos and in the way of working of a clinical team, as well as the establishment of working routines that facilitate family involvement approaches.

# **Strengths and Limitations**

Our study:

- Can inform policies and guidelines on family involvement so that they impact on routine practice.
- Is novel in covering a wide range of family involvement practices, highlighting common barriers, problems and facilitators.
- Synthesises rich qualitative data from professionals, patients and families.
- Could not include subgroup and quality analyses, due to the high correspondence between type of family involvement practice and methodology.
- May be conceptually limited as extant research has focused on perspectives of staff involved in family work and few studies are available on families' views.

#### Key words:

Carers; Psychosis; Severe mental illness (SMI); Family Intervention (FI); Implementation

Word count: 4,451 (excluding title page, abstract, references, figures and tables)

#### BACKGROUND

The process of deinstitutionalisation of mental health care in the western world has led to families and others in the community shouldering the psychosocial burden of care and informally adopting the role previously provided by professionals in health care services [1-3]. The adoption of protected terms such as 'carer' in the United Kingdom (UK) and 'caregiver' in the United States (US) is a response to the substantial, yet 'non-professional', role that individuals in a close relationship have in supporting a person receiving mental health treatment. The term may include parents, partners, siblings, children, friends or other people significant to the individual: essentially, anyone who provides substantial support without being paid. The term carer can be problematic, being considered by some to have connotations of dependency and of minimising the significance of the relationship [4]. Also, many 'carers' do not self-identify as such, and consider their caring role as being within the traditional responsibilities expected of them. To avoid confusion when referring to family-directed initiatives, the single term 'families' will be adopted throughout this review, and broadly applies to a person's social network, not excluding their non-blood relatives.

<sup>4</sup>Family involvement' in mental health services can take different forms, depending on the level of need and availability of services. Generally, it can be conceived on a spectrum from more basic functions to specialised interventions, the minimal level including the provision of general information on the mental health service and assessments. On a more complex and specialised level, services can offer families psychoeducation, consultation, Family Interventions (FIs) and therapies [5]. There are both strong economic and moral imperatives to establish meaningful involvement and true collaborative working between families and health professionals. These are recognised by international government policies and psychiatric guidelines stipulating that families should be supported and actively involved in psychiatric treatment [6-11]. Families can encourage engagement with treatment plans, recognise and respond to early warning signs of relapse [12] and assist in accessing services during period of crisis [13-15]. Family involvement can lead to better outcomes from psychological therapies [16] and pharmacological treatments [17], fewer inpatient admissions, shorter inpatient stays, and better quality of life reports by patients [18-21].

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However, despite the vast evidence base for Family Intervention [22-28] and Family Psychoeducation [29], evidence suggests that family involvement is often not implemented in routine mental health care. There is an abundance of both quantitative and qualitative studies into experiences of inpatient care reporting that families feel marginalised and distanced from the care planning process. Common themes across international studies indicate that families feel isolated, uninformed, lack a recognised role and are not listened to or taken seriously [1, 30-43]. Families also commonly report feeling that confidentiality is used by professionals as a way to not to share information [39, 44]. Family Intervention as a treatment approach is startlingly under-implemented, with extremely low numbers of families actually receiving it in clinical services [11, 45-47]. It is the case that for many, contact between professionals and families remains limited to telephone calls during crisis periods [48].

Why is family involvement in treatment so under-applied? There has been much debate about the reasons (e.g. [22, 49-51]) and some suggest they are linked to general problems of implementing new evidencebased practices in clinical services [29]. Other proposed barriers are more specific to family interventions, such as the danger of increasing burden related to caregiving, role strain, lack of experience and/or interest [52] and the complexities of navigating confidentiality [53]. Such discussions are largely speculative and reviews of evidence tend to focus on the provision of specific interventions, such as Family Psychoeducation [29] or Family Intervention [54]. This systematic review aims to assess how the involvement of families is implemented in the treatment of patients with psychosis, taking a broad view of involvement as described above in order to capture the barriers, problems and facilitators that are operating in practice. In doing so, this may help to better define and implement families' involvement in psychiatric treatment in the future.

#### **METHODS**

#### **Identifying relevant studies**

Computerised databases were searched for eligible studies: MEDLINE, EMBASE, PsycINFO, AMED (via Ovid), BNI and CINAHL (via HILO), Social Sciences Citations Index (via Web of Knowledge) and CDSR,

DARE and CENTRAL (via the Cochrane Library). Word groups representing patient diagnosis, intervention and involvement terms and outcome descriptors were combined in several ways. Strategies were adapted for each database, using controlled vocabulary (MeSH, Emtree, Thesaurus of Psychological Index Terms) and free text (see Supplementary File). The search was last repeated on 01/06/2014.

Publication bias was minimised by including conference papers and book chapters, searching grey literature for dissertations and reports (ETHOS, SIGL) and corresponding with authors to identify further works. Both backward snowballing (from the reference lists of included studies and identified reviews) and forward snowballing (finding citations to the papers) was conducted.

# **Inclusion procedure**

A study was eligible for inclusion if: 1) it was an original collection of data; 2) situated in primary or secondary mental health services; 3) the patient population included people being treated for psychotic disorders<sup>1</sup>; 4) the intervention involved tripartite communication between health professionals (any), families (unpaid carers) and adult patients, excluding those focused exclusively on professional–family communication, family-family communication or multiple-family groups; and 5) results described barriers, problems and/or facilitators to involving families in treatment. No study type was excluded, however only Latin-script languages were able to be translated.

"Barriers" were defined as factors that prevented an approach from taking place or limited the scope of it, "problems" referred to issues that emerged when delivering an approach and "facilitators" were considered to be any factors that aided implementation or delivery. "Family involvement" was defined inclusively as any process allowing health professionals, families and patients to actively collaborate in treatment, such as in making joint treatment decisions. Studies not reporting clear information on how families were involved in treatment were excluded. Studies into general experiences, opinions, satisfaction or needs were also excluded, unless they related to a clearly described specific involvement in treatment.

<sup>&</sup>lt;sup>1</sup> Attempts were made where possible to focus on patients with psychosis, however many studies used opportunity sampling of mixed 'severe mental illness' groups, which were included in order to be as inclusive as possible.

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Two reviewers (EE and DG) screened all of the titles and collected relevant abstracts. These were screened and then discarded if they did not fit the selection criteria. Studies that seemed to include relevant data or information were retrieved and their full text versions analysed and examined for study eligibility. All final full text choices were confirmed and agreed by both reviewers.

#### Method of Analysis

Data extraction and synthesis was guided by the *Economic and Social Research Council (ESRC)*'s Guidance on the Conduct of Narrative Synthesis in Systematic Reviews [55].

The included studies used both qualitative and quantitative methods, yet clearly had conceptual overlaps despite reporting results in different formats. Any available quantitative data was usually descriptive, reported in addition to qualitative findings and was largely used to explore existing themes or concepts. It was therefore considered appropriate to transform quantitative findings into qualitative form to systematically identify the main concepts across the studies using thematic analysis [55 , 56]. The use of this method is increasingly being advocated with studies involving data that is quantitative or from mixed methods [56-58] to address questions relating to intervention need, appropriateness and acceptability in systematic reviews [59].

# Data extraction and synthesis

Theoretical Thematic Analysis [60] using inductive themes to identify the barriers, problems and facilitators of family involvement was used as a framework to explore further themes.

Two non-clinician researchers (EE and AD) independently extracted author interpretations and participant data from the included studies using a piloted data extraction sheet. They then separately allocated the findings to relevant sections of the framework (e.g. "barriers according to staff perspectives") and coded the

data within each section. Identified categories (e.g. 'unsupportive attitudes of managers') were aggregated into subthemes (e.g. 'Attitudes towards family work') and finally became grouped under overarching themes (e.g. 'Context: Addressing Organisational Culture'). These emerging themes were discussed throughout analysis along with a clinician-researcher (DG), and discrepancies were resolved through iterative discussions. Robustness of the synthesis was investigated and themes were checked for completeness. Two clinician-researchers (DG and SP) acted as third party assessors of the final data synthesis.

# RESULTS

#### **Included studies**

Database searching produced 9950 titles to screen. After removing duplicates and irrelevant papers, a full text assessment of 119 documents was conducted. Twenty eight publications met our inclusion criteria and second stage searching including grey literature searching, personal correspondence and snowballing techniques led to the further identification and inclusion of 15 articles. This brought the final number of documents to 43. The PRISMA flowchart in Figure 1 depicts the identification and exclusion of articles. (Insert Figure 1 here)

# **Overview of papers**

Forty papers were published between 1991-2013 and one in 1978. Just over half of the studies were based on UK findings, with the rest from Finland, the USA, Italy, Australia, Canada, Germany, India, New Zealand, Spain, Greece and Portugal. Mainly, papers reported on experiences of implementing Family Intervention approaches (n=33). Typically these followed a similar structure and were broadly modelled on the Behavioural Family Therapy approach [61] (see Supplementary File for full study characteristics). This included variations such as 'Psychosocial Intervention' and 'Family Psychoeducation' that fit the model of a Family Intervention. The remainder explored Open Dialogue approaches (n=6), Systemic Psychotherapy (n=5) and one purely Behavioural Therapy programme. The vast majority were cross-sectional studies and 13 were naturalistic evaluations, descriptions or case studies of a service. In all, 37 papers explored staff

perspectives, eight papers featured patient perspectives and six featured 'family' perspectives. In total, the review included data of 588 professionals, 321 patients and 276 'family members' or 'families'.

# In depth review: Synthesis across studies

Figure 2 summarises the final cross-study synthesis: the identified barriers/problems (in red) and facilitators (in green) and the themes in which they seemed to be operating. The themes closely relate to temporal sequencing in the process of delivering an intervention: the *context, engagement*, and then *delivery*. The figure provides a visual representation of the matches and gaps between barriers and facilitators related to involving families. This is for the most part conceptual, as barriers and their direct facilitators may not have been discussed in the same study. The themes and sub-themes are explored in greater detail in the synthesis below, which includes details of problems associated with delivering approaches that involve families as well as barriers and facilitators of this work.

(Insert Figure 2 here)

# Context: Addressing the Organisational Culture

This theme reflects the majority of the findings, mostly from staff perspectives. Their experience implementing family work could be characterised as working in relative isolation in a system where colleagues and managers did not value and prioritise family involvement or were openly hostile to it. With multi-disciplinary co-operation and working systems not in place, practical burdens associated with family work were sometimes insurmountable. Mirroring this, factors that enabled family involvement to take place were related to top-down management support, prioritisation and changing the culture of family work.

Organisational Attitudes and Paradigms

This subtheme covered general attitudes, such as family involvement not being valued at organisational and team level but also highlighted possible entrenched reasons for this. For example, individualistic, biological paradigms made family work seem secondary or optional [62-64] and staff found it difficult to adopt a collaborative stance, relinquishing the role of didactic problem solver [63]. In some cases, it appeared that historical negative attitudes towards families had not shifted [62, 64]. Anti-family work attitudes described amongst colleagues ranged from resistance towards the approaches [63, 65-68] to well-intentioned but complicating beliefs regarding clinicians' duty towards the patient [64, 69, 70]. Facilitators related not only to specific strategies but to an overall shared culture and prioritisation of family work [64, 71, 72], shifting attitudes towards viewing the family as equal partners [71, 73] and thinking more systemically about problems [71, 74].

#### Practical Needs Associated with Family Work

Overwhelmingly, staff reported on the practical burdens of family work: that it requires time, resources and funding and is difficult to integrate with other clinical casework [62, 64-70, 73, 75-87], particularly in areas with high demands and clinical crises [73, 82, 83]. Specific needs reported for family work included flexible hours [64, 65, 67, 70, 80, 82-84, 87-90] and the accommodation of family requirements such as childcare facilities [80] or home visits [82, 89, 91]. A lack of systems and structure for carrying out and recording family work was also reported as a barrier to implementation and problem during delivery [63, 87, 92]. This included a lack of co-ordination between inpatient and outpatient care [62]. These issues were compounded by reports of services and managers not making time allowances for family work e.g. not providing time in lieu for out of hours work [64, 65, 77, 83, 84] or obstructing time use e.g. by refusing the release of staff for training [63].

#### Management Culture

Commonly, staff reported on the unsupportive attitudes of managers and colleagues as limiting the implementation of family involvement [63, 64, 66, 77-79, 87, 92, 93]. This ranged from a *"management culture of benign neglect rather than of active opposition"* [93] to overt challenges such as not respecting

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ring-fenced time for family work [87]. The strongest facilitator seemed to be that of strong leadership

through senior management support and developing strategic solutions. This "sanctioned" family work, giving it core priority status within the service [64], and could facilitate specific powerful initiatives such as writing family work into business plans, policies and job descriptions of all staff [63, 79]. Further endorsement came from providing flexible hours, creating new staff roles and financial provision [63, 73, 79, 94]. The value emerged of having regular multi-disciplinary meetings to address team-specific needs [72, 78, 79, 88] and developing strategies that prioritised family work and made it a part of regular clinical practice [63, 72, 73, 79, 88, 94]. This included having routine assessment of all families, asking clinicians about families when reviewing caseloads and providing regular feedback of family data to teams and managers [63, 94].

#### Training Needs

Staff also reported on lacking access to adequate supervision and training[62, 63, 65, 66, 83, 86, 87, 92] as barriers to implementation. This may link with reports of staff lacking skills or confidence to do the work [62, 64, 85, 86, 92]. Some problems during delivery (such as managing family dynamics [64, 65, 70, 74, 78, 88, 95]) could also be related to staff skills and experience [71, 78, 81]. As expected, having a structured regime of supervision, encouraging attendance and ongoing support was described as helping staff to deliver work with families [63, 72, 78, 79, 88]. Staff also reported on the value of belief in the approach and having an identity in their role [71, 72, 79, 81, 86].

Team Attitudes, Commitment and Multi-disciplinary Co-operation

Difficulties arose when only a minority of team members had been trained in an intervention [82]. Staff reported that collaboration was often lacking [63, 65, 69, 73, 77, 80] and that involving families requires whole team commitment [76, 82]. 'Ownership' was sometimes an issue, with various staff groups perceiving family work as within the domain of other roles, not theirs [69, 80]. Role and team-specific issues also emerged, such as psychiatrists, inpatient staff and home treatment teams being less involved [63,

66, 73, 81]. Collaboration in the form of multi-disciplinary co-working, peer-supervision and whole team approaches were all reported as aids to implementing family work [63, 66, 71-74, 78, 79, 82, 88].

Problems with finding 'appropriate' referrals were reported widely [65, 67, 68, 77, 78, 80, 82, 83, 93]. Whilst some patients do not have families, the pervasiveness of this response also called into question staff members' pre-existing ideas about what constitutes an 'appropriate' family for intervention. Staff reported the resistance of other professionals to make referrals [67, 88], family work services being "forgotten" and referrals being made as a "last resort", by which time the families themselves may have grown resistant [93]. Acting as a facilitator was the promotion of family work, both as a cascading effect through colleagues and across services [64, 79, 87].

# Engagement: Addressing Concerns through Openness, Encouragement and Building Alliance

The next theme related to the process of engagement, informed more broadly by both staff and family responses. A picture emerged of families sometimes being reluctant to engage, and of valid concerns. Yet the successful establishment of trusting relationships indicates these concerns may be surmountable in many cases.

# Reservations about Involving Families

Similar issues around the nature of involving families emerged as a barrier to families becoming involved and as problems during treatment. Some concerns seemed linked to fears around power and control: bidirectional privacy concerns (keeping the extent of the illness from the family and family issues from services) [70] and patient fears of placing relatives in a position of power [70, 95] or exposing one's vulnerability [75]. Responses in all three participant groups addressed the need for an exclusive patient-professional relationship [69, 70, 76, 95]. Existing individual and family problems (such as patient symptoms being directed at family members [62]) also precluded family involvement. Both families and staff expressed fears of making the current situation worse, such as by burdening the family and worsening

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the patient's symptoms [70, 80, 84, 86, 91]. Professionals described building trust and rapport, through open discussions with the family, acknowledging concerns and providing reassurance [71, 74, 88, 91].

# Problems Engaging Families

These were often unspecified as scepticism, lack of motivation or refusal from the families, occurring prior to engagement or during treatment [65, 76, 78, 83, 84, 88, 93, 96]. As professional responses, these may reflect their attitudes towards families as unmotivated, but also describe the failure of the team to mobilise the family in favour of treatment [96]. A factor described as a facilitator was having a critical period of engagement: intensive efforts at contact and involvement early on after contact with services [93, 96-99] and presenting the approach enthusiastically [71, 89] functioned to establish collaborative relationships between families and professionals as the modus operandi.

# Delivery: Active Collaboration, Professional Skills and Respect for Families as Individuals

The final theme related to factors that affected how staff members delivered family interventions and how families experienced them. As a whole, both family and staff responses highlight the important of respectful, equal partnership, enhanced by professional skills and experience.

# Working Relationships Between Families and Professionals

Collaboration between families and professionals on an equal footing appeared valued by both families and professionals. Lack of collaboration was cited as a problem during delivery, resulting in families feeling patronised or not understood[76]. Open Dialogue papers particularly emphasised the lack of success when actions were unilaterally decided, rather than emerging from a joint process [74, 99]. Factors helping to overcome this included being able to relinquish control, i.e. tolerate uncertainty in order to allow a joint solution to emerge [78, 96, 98-100], approaching the family on an equal basis [71] and actively collaborating with families during meetings [66, 71, 89, 92, 96].

How families experienced an approach closely linked with their experience of the professional. Some families reported experiencing an approach as negative or critical, both through the model itself e.g. its characterisation of illness [101], or experiences of the professional, perhaps as criticising parenting [101, 102]. Yet the interpersonal qualities of the professional and the establishment of a therapeutic alliance strongly emerged as facilitators: professionals being informed, genuine, warm, non-blaming [71, 89, 101] and demonstrating an awareness and understanding of the problems of the whole family [71, 79, 89, 90, 99].

A lack of continuity was cited as a problem [99], whilst a facilitator was having the same team involved from the beginning and staying with the family throughout the treatment process [96, 98, 99].

# Individualisation within the approach

Approaches were sometimes described as culturally insensitive [76, 88]: rigid, manualised approaches did not meet the general needs of particular groups whilst individual needs, such as illiteracy, were sometimes not catered to [64, 76, 97, 103]. Professionals and families valued having a clear structure whilst allowing for flexibility [71, 76, 88, 99]. Professionals' skills were also important, by way of communicating information in an easy-to-understand format, avoiding jargon [71, 88, 89, 99] and developing an individualised and contextualised approach [71, 76, 88, 93, 99].

#### Working with Complex Needs

Professionals highlighted the complexities of working both with families and with patients with psychosis. The difficulties of managing patient symptoms and working in a meaningful way with their beliefs [73, 104] may be compounded by family dynamics [64, 65, 70, 74, 78, 88, 95, 104] and potentially relatives' own emotional and affective problems [104]. Staff members' qualities, skills and experience in the area were naturally described as facilitators [71, 76, 78, 79, 81, 83, 89, 90, 100]. Perhaps unsurprisingly, useful skills were described as working creatively to overcome barriers, hypothesising, reflecting and persevering [71, 79, 100].

#### DISCUSSION

# Main findings

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Our results suggest that having 'top-down' support and training part of the staff to family work is necessary but not sufficient. In order to effectively implement family involvement in care, all members of a clinical team should be trained and regularly supervised and a 'whole team approach' should be used. Developing a clear structure for the intervention may be beneficial for the delivery of family involvement, provided that flexibility to accommodate individual needs is ensured. Concerns emerged regarding privacy, power relations, fear of negative outcomes and the need for an exclusive patient-professional relationship. Exploring and acknowledging such concerns through open, yet non-judgemental communication could facilitate the establishment of a therapeutic alliance between staff, families and patients.

The findings may help to explain why family interventions – despite their overwhelming evidence base and their inclusion in practically all policies and guidelines – are so poorly implemented in routine practice. The requirements identified may be challenging given that family-oriented practice may need to be embraced by a whole organisation and included in work routines in order to be implemented.

# **Strengths and limitations**

To our knowledge, this is the first systematic review that specifically focused on barriers, problems and facilitators of implementation of family involvement in the treatment of patients with psychosis. This is of strong importance given the current climate of government policies and psychiatric guidelines stipulating that families should be supported and actively involved in psychiatric treatment [6-11], and the disappointments in achieving this in practice so far. The search strategy allowed for the capture of a large number of studies, different researchers independently extracted and reviewed the data and when necessary authors were contacted to clarify ambiguous information. The use of thematic analysis, described as having the "most potential for hypothesis generation" [108], allowed for understanding the larger picture, which is more than the sum of the findings. Whilst interpretative, this process has been carried out in accordance with RATS guidelines [61] and presented transparently. Though some themes were not highly recurrent -for example criticisms of manualisation emerged only in structured approaches such as Behavioural Family Therapy- in all, findings were complimentary, not contradictory. The fact that common themes emerged in

spite of variations in approach, across 14 countries, speaks for the robustness of the findings as representing shared issues with family involvement.

However a number of limitations must be considered while interpreting the results of this study. Methodologically, conducting sub-group analysis, i.e. for different intervention models, was not considered viable due to the strong association between type of approach and methodology used e.g. Open Dialogue with case studies and Behavioural Family Therapy with the Family Intervention Schedule (FIS) questionnaire. Carrying out a sub-group analysis may have therefore had the risk of mischaracterising certain approaches due to variation in the richness of data. Whilst there are well-established methods for assessing the quality of intervention studies, this is not the case for studies of implementation processes, qualitative or mixed methods research [56] and the use of appraisal tools in qualitative research remains contentious [109, 110]. The decision not to use quality-based analysis was therefore also based on recognition of the important contribution and explanatory value that descriptive accounts offer. Despite efforts to find grey literature, the search strategy may still have been limited in its bias towards published research, yet the nature of this review topic means that service level audits and evaluations are likely to be of relevance. Conceptually, the dominance of staff and academic perspectives may have led to barriers within the organisation being explored most thoroughly, however does not lead to the conclusion that there are no inherent problems with involving families in clinical settings.

# Comparison with available literature and implications for practice

Our findings reflect important key features for implementation of evidence based practices (EBP), already identified in previous research in implementation science, such as top-down input and leadership and the need for continuing consultation and training [105] The presence of management and leadership decisions and strategies operating as barriers and facilitators throughout the organisational context-both directly and indirectly-aligns with findings that leadership at all levels (e.g., executive director, middle manager, clinical supervisor) is associated with innovation [106], implementation of evidence based practice (EBP) [107], and with improving the organisational context for EBP implementation [108].

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The fundamental role of the organisational context is emphasised in the literature with both culture (the normative beliefs and shared expectations of the organisation) and organisational climate (the psychological impact of the work environment on the professional) strongly moderating the uptake of evidence based practices [109]. The practice to be implemented must match the mission, values, tasks and duties of the organization and individuals within that organization [110]. The absence of a strong organisational culture favouring family work may be influenced by traditional paradigms based on the predominance of biological models of mental illness, which tend to minimise the focus on the individual's social context [50]. Also, the characterisations of families as dysfunctional and sometimes even as 'the cause of psychiatric illness', despite being widely rejected [111], may have contributed to a loss of trust in services and strained relationships between professionals and families [112]. This may explain the importance and the effort required in building alliances, which emerged in our findings. Clinicians may uphold the patient-professional alliance by addressing concerns regarding privacy and by being mindful that patients do not perceive a loss of power due to having family involvement in their care.

# **Future directions for research**

So far the findings reflect more what can go wrong than real evidence of successful implementation. For example, sustainability has not been addressed in the review as this stage has hardly been reached. More research will be needed to see which organisational steps can actually change the culture in a service so that family intervention happens, not only in a research study or with some patients, but with all families, every day, and over longer periods of time.

Future studies should attempt to better capture wider views, particularly in-depth understanding of patients' and families' views. This may also enable insight into the potentially varied experiences of minority groups. These views may be best obtained outside of group interviews, in which a power imbalance may be present.

There would be value in exploring the views of professionals who have not already demonstrated commitment to family work.

Despite a 'whole team approach' seeming to be the way forward for a widespread implementation of family work, there is a need to obtain insight into the organisational challenges that may be related to this and to develop clear practical guidelines for the reorganisation of clinical teams.

**Funding:** The research was partially funded by the National Institute for Health (NIHR) Research Collaboration for Leadership in Applied Health Research and Care (CLAHRC) North Thames at Bart's Health NHS Trust.

Competing interests: The authors declare they have no competing interests.

**Authors' contributions:** DG, EE and SP contributed to the conception and design of the study. EE designed and conducted the search, DG and EE selected the studies. AD and EE extracted data and carried out the thematic synthesis. EE wrote the manuscript, AD and DG reviewed and edited the manuscript and SP provided critical review of the manuscript. All authors contributed to and approved the final submitted version.

Acknowledgements: Noneb

Data Sharing Statements: No additional data available

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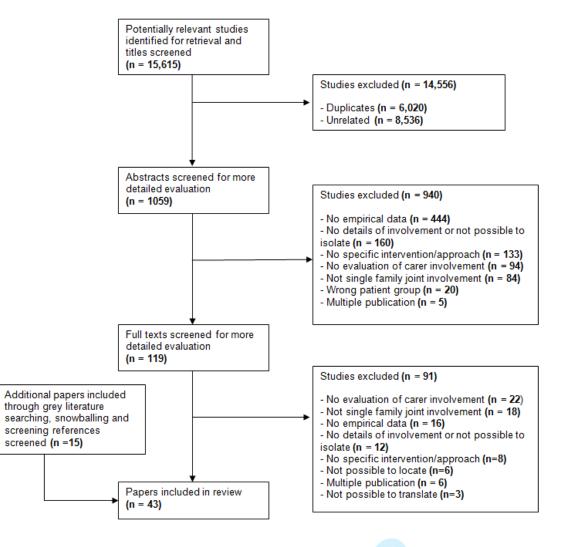
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# Figures & Table Legends

- Figure 1. PRISMA flow diagram for paper selection
- Figure 2. Barriers, problems and facilitators to family work. Summary of themes
- Supplementary File 1. Protocol for Systematic Review
- Supplementary File 2. Modified database search strategies
- Supplementary File 3. Characteristics of included studies (n=43)

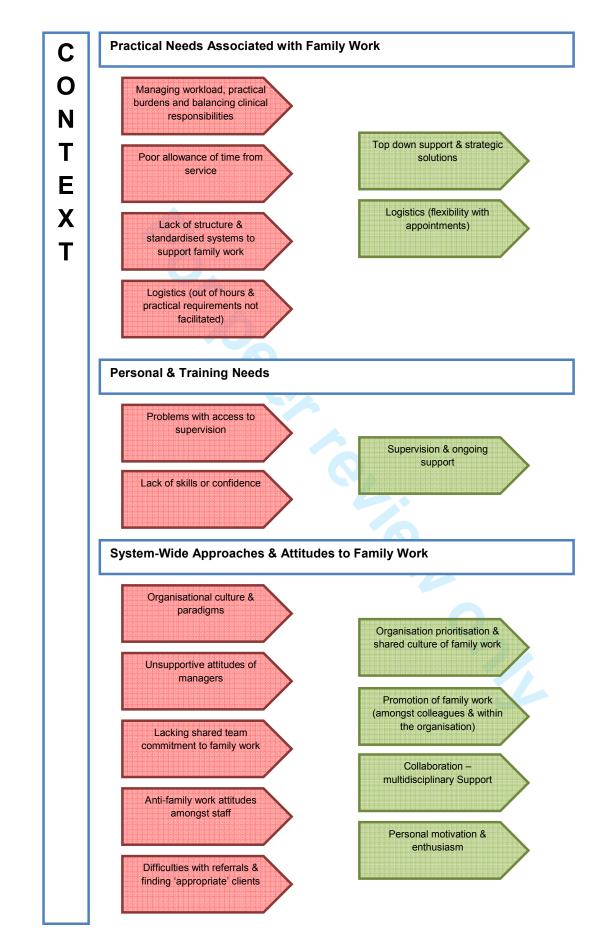
# **Fig.1** PRISMA flow diagram for paper selection

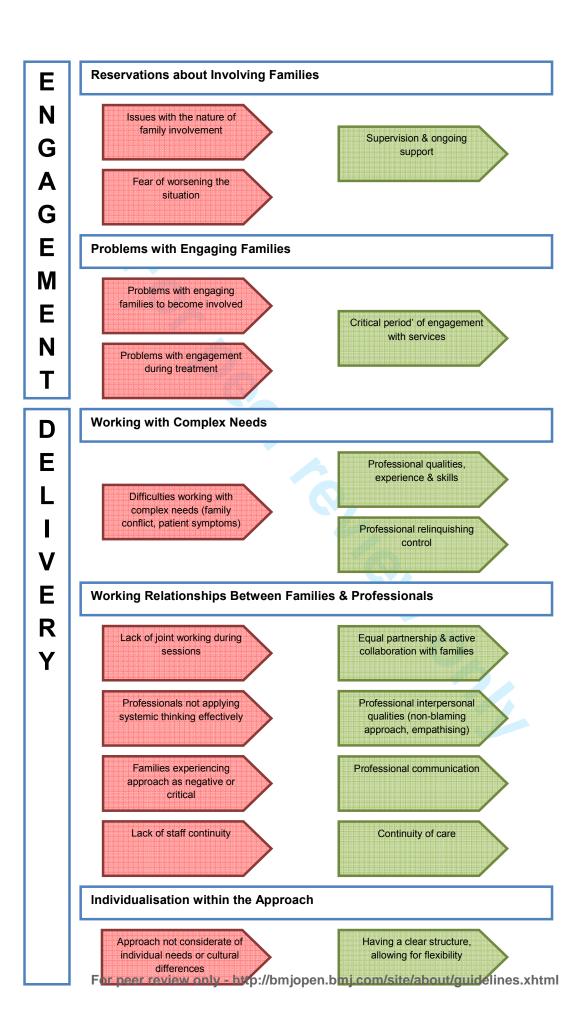


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Figure 2. Barriers, problems and facilitators to family work. Summary of themes





# Supplementary file: Protocol for a Systematic Review

# Implementing family involvement in treatment of psychosis: A Systematic Review of facilitators and hindering factors

Domenico Giacco, Erica Eassom & Stefan Priebe

# Background and rationale for a review

Due to the move of psychiatric care from hospitals to community, nowadays informal caregivers (i.e. family or friends) have taken some functions performed in the past by psychiatric institutions. Consequently, "informal care" plays a significant role in development and evaluation of health programs and policies (Clark & Drake, 1994; Simpson, 2008; Caqueo-Urizar et al., 2009).

An estimated 40-50% of almost six million carers in the United Kingdom provide care for another family member or friend with a mental health problem (Office for National Statistics 2003). In particular, it has been estimated that carers of people with schizophrenia save the public purse £1.24 billion per year (Schizophrenia Commission Report, 2012).

Many psychiatric policies and guidelines stipulate that families should be supported and actively involved in psychiatric treatment (Department of Health, 2006; National Institute of Mental Health in England, 2004; NICE, 2011). The Schizophrenia Commission Report (2012) states that "Services need to make a fundamental reappraisal of how they treat families and put them at the centre of their thinking and practice". This document also emphasizes that "carers are seen as resource, experts, partners in care". Recent evidence from large scale European and UK studies has documented that relatives wish to be more involved in the care of their ill relatives, also during acute phases of their illness (Jankovic et al., 2011; Giacco et al., 2012).

Family involvement in treatment is often seen as intrinsically worthwhile; however some positive consequences in terms of patients' outcomes and patients and families' satisfaction with treatments have also been hypothesized (Simpson and House, 2003).

However, a number of barriers to family involvement in treatment and problems in its implementation in routine practice have been also identified (Simpson and House, 2003) such as: danger of increasing burden related to caregiving, role strain, lack of experience and/or interest. Also, specific problems may arise in different phases of the illness (e.g. when the patient is acutely ill and requires involuntary treatment).

This study will systematically review the available studies exploring carers' involvement in routine psychiatric treatment. Assessing barriers, problems and facilitators related to family involvement will help better define and implement family involvement in clinical practice.

# **Research questions**

The review will aim at answering the following research questions:

- 1. What are the barriers that may prevent family involvement?
- 2. What are the problems that may arise during implementation of family involvement?

3. What are the facilitators of family involvement?

The different perspectives of patients, their family members and staff will be assessed.

# **Selection criteria**

# 1) Study type

Conducted in general public mental health services Any type of study design (qualitative, quantitative and mixed) Published in Latin script

# 2) Participants

# Patients

People with psychotic disorders (F20-29 and F31 according to ICD-10) Age 18-65/ any gender/nationality

# Family/Carers

Family and informal (i.e. non-professional) carers: relatives, friends, others Any age /gender/nationality Either main carer (i.e. spending most time with the patient) or other carers

# Staff

Any mental health professional (psychiatrists, psychologists, nurses, social workers, care coordinators, occupational therapists)

# 3) Family involvement

Explicit description of family involvement (i.e. information, support, involvement in decision making, preparation of crisis plans, etc.) Assessment of carer's involvement through assessment of barriers or problems or facilitators or feasibility

# Exclusion criteria

- 1) Studies assessing family involvement in planning of services will be excluded
- Studies not reporting clear information on how family involvement was implemented (services' catchment area, description of activities, i.e. information, support, involvement in decision making, preparation of crisis plans, etc.)
- 3) Studies into general experience, opinions, satisfaction or needs, unless related to a clearly described carer involvement in treatment
- 4) Studies reporting on therapy for the family or group psychoeducation, i.e. the carer involvement will have to be in the context of the treatment of an individual patient

# Methods

In order to gather relevant literature, electronic searches of electronic databases will take place. In addition, the articles included as references in the review papers found will be hand searched too.

Databases to be searched include:

- BNI
- CINAL
- EMBASE
- MEDLINE
- PsychINFO
- CENTRAL
- AMED
- Social Sciences Citations in Web of Knowledge

Hand searching of review articles on the topic and of included studies Grey literature will also be searched, including:

- Dissertations/PhDs
- Contacting authors in the field
- Forward and backward snowballing related to citations

The abstracts of the papers identified will be examined to determine papers potentially relevant to the review. Based on this initial screening, selected full-text articles will be obtained for a second-stage screening. Studies will be included and submitted for data extraction if they specifically address family involvement in the treatment of patients with psychosis and if the tasks in which the family is involved are specifically described.

#### **Extraction process**

Search terms will be a mixture of family/carers' involvement descriptors, psychosis descriptors and outcomes.

Family/Carers' involvement descriptors	Psychosis descriptors	Outcome descriptors	
Carers	Psychosis	Clinical outcomes	Experiences
Caregivers	Schizophrenia	Symptoms	Benefits
Relatives	Psychotic disorders	Hospitalizations	Rewards
Friends	Schizoaffective disorder	Quality of life	Failures
Family support	Schizophreniform disorder	Adherence	Challenges
Family burden	Severe mental illness	Satisfaction with treatment	Difficulties
Involvement	Acute phase	Care	Barriers
Social support	Crisis	Satisfaction	Stress

Practical support	Experiences	Empowerment
Inpatient treatment	Service provision	
Outpatient treatment	Psychiatric services	
Involuntary	Opinions	
hospitalization	Opinions	
Psychoeducation	Attitude	

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Supplementary File. Modified database search strategies

#### EMBASE/MEDLINE/PSYCHINFO/AMED via Ovid

- 1. exp schizophrenia/ or exp psychosis/
- 2. 1 use emez
- 3. exp schizophrenia/ or exp psychotic disorders/
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- 5. exp psychosis/ or schizoaffective disorder/
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- 7. exp bipolar disorder/
- 8. (psychos#s or psychotic or schizo\$ or bipolar disorder).ti,ab.
- 9. ((chronic\$ or serious or severe\$) adj (mental\$ or psychological\$ or psychiatric) adj (disorder\$ or ill\$ or health or problem\$)).mp.
- 10. Or/2,4,6-9
- 11. ((famil\* adj2 therapy) or family psychiatry or family psychotherapy or family counselling or family work or family treatment or family intervention or family management or family approach\$).mp. [mp=ti, ab, sh, hw, tn, ot, dm, mf, dv, kw, nm, kf, ps, rs, ui, tc, id, tm]
- 12. ((carer or caregiver\$ or relative\$ or friend\$ or family or families) adj2 (partner\$ or work\$ with or support\$)).mp.
- ((carer\$ or caregiver\$ or relative\$ or friend\$ or family or families) adj5 (program\$ or psychoeducation\$ or integrate\$ or train\$ or inform\$ or service\$ or intervention\$ or initiative\$ or psychosocial)).mp
- 14. ((carer\$ or caregiver\$ or relative\$ or friend\$ or family or families) adj (involv\$ or inclu\$)).mp.
- 15. or/11-14
- 16. (benefit\$ or advantage\$ or success\$ or fail\$ or problem\$ or disadvantage\$ or challenge\$ or barrier\$ or difficult\$ or issue\$ or experience\$ or satisf\$ or evaluat\$ or obstacle\$).ti,ab.
- 17. 10 and 15 and 16

#### **BNI/CINAHL via HILO**

- (psychos?s OR psychotic OR schizoaff\* OR schizophr\* OR "bipolar disorder" OR "manic depression" OR "severe\* mental\* ill\*" OR "severe\* mental\* disorder\*" OR "serious\* mental\* ill\*" OR "serious\* mental\* disorder\*" OR "severe mental health" OR "serious mental health").ti,ab
- ("family therapy" OR "family psychiatry" OR "family psychotherapy" OR "family counselling" OR "family work" OR "family treatment" OR "family intervention" OR "family management" OR "family approach\*").ti,ab,mw,su
- ((carer\* OR caregiver\* OR relative\* OR friend\* OR family OR families) AND (partner\* OR "work\* with" OR support\* OR program\* OR psychoeducation\* OR integrate\* OR train\* OR inform\* OR service\* OR intervention\* OR initiative\* OR psychosocial OR involv\* OR inclu\*)).ti,ab

- 4. 2 OR 3
- (benefit\* OR advantage\* OR success\* OR fail\* OR problem\* OR disadvantage\* OR challenge\* OR barrier\* OR difficult\* OR issue\* OR experience\* OR satisf\* OR evaluat\* OR obstacle\*).ti,ab
- 6. 1 AND 4 AND 5

#### Social Sciences Citations Index via Web of Knowledge

1. TS=(psychosis OR psychoses OR psychotic OR schizoaff\* OR schizophr\* OR "bipolar disorder" OR "manic depression" OR "severe\* mental\* ill\*" OR "severe\* mental\* disorder\*" OR "serious\* mental\* ill\*" OR "serious\* mental\* disorder\*" OR "severe mental health" OR "serious mental health")

2. TS=("family therapy" OR "family psychiatry" OR "family psychotherapy" OR "family counselling" OR "family work" OR "family treatment" OR "family intervention" OR "family management" OR "family approach\*")

3. TS=((carer\* OR caregiver\* OR relative\* OR friend\* OR family OR families) AND (partner\* OR "work\* with" OR support\* OR program\* OR psychoeducation\* OR integrate\* OR train\* OR inform\* OR service\* OR intervention\* OR initiative\* OR psychosocial OR involv\* OR inclu\*))

4. #2 OR #3

5. TS=(benefit\* OR advantage\* OR success\* OR fail\* OR problem\* OR disadvantage\* OR challenge\* OR barrier\* OR difficult\* OR issue\* OR experience\* OR satisf\* OR evaluat\* OR obstacle\*)

6. #1 AND #4 AND #5

Refined by: [excluding] Research Areas NEUROSCIENCES NEUROLOGY OR PHARMACOLOGY PHARMACY OR GENERAL INTERNAL MEDICINE OR PEDIATRICS OR GERIATRICS

#### CDSR/DARE/CENTRAL via the Cochrane Library

- 1. . MeSH descriptor: [Schizophrenia] explode all trees
- 2. MeSH descriptor: [Psychotic Disorders] explode all trees
- 3. MeSH descriptor: [Bipolar Disorder] explode all trees
- 4. MeSH descriptor: [Affective Disorders, Psychotic] this term only
- 5. (chronic or serious or severe) next (mental or psychological or psychiatric) next (health or disorder or ill or problem) (Word variations have been searched)
- 6. Psychosis (Word variations have been searched)
- 7. {or #1-#6}

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- 8. (family next therapy) or (family next psychiatry) or (family next psychotherapy) or (family next counselling) or "family work" or (family next treatment) or (family next intervention) or "family management" or "family approach\*" (Word variations have been searched)
- 9. (carer OR caregiver OR relative OR friend OR family) NEAR (partner OR "work\* with" OR support OR program OR psychoeducation OR integrate OR train OR inform OR service OR intervention OR initiative OR psychosocial OR involve OR include) (Word variations have been searched
- 10. benefit or advantage or success or fail or problem or disadvantage or challenge or barrier or difficult or issue or experience or satisf\* or evaluate or obstacle)
- 11. #8 or #9
- 12. #7 and #10 and #11 in Cochrane Reviews (Reviews and Protocols), Other Reviews and Trials

Supplementary Table 1. Characteristics of included studies (n=43)

Country of origin, language, year of publication	Published Form	Principal objective of the study	Operationalisation of family involvement	Type of psychiatric service	Study design eliciting barriers and facilitators	Participants data used in review	Methods relevant to review
publication					lacintators		
UK(England), English, 2013 [98]	Journal Article	To explore the meaning and significance of FI for the individual who experiences psychosis, and its significance for recovery.	Family Intervention. 'Integrated Family Intervention'; 'S.T.E.P. Service' individual and family CBT with systemic perspective: psychoeducation, needs assessment for further FI: problem solving, behavioural goal setting, medication management, relapse management, skills training.	Specialised (Family Intervention Service), Outpatient	Cross- sectional, Qualitative	7 individuals with experience of psychosis and the FI service: Diagnoses included schizophrenia, bipolar disorder, and severe depression	Semi-structured interviews
New Zealand, English, 1997 [63]	Journal Article	To measure the implementation of the 'Integrated Mental Health Care' approach 1 year after training and explore barriers and benefits, and provide information about participants' perceptions and experiences.	Family Intervention. 'Integrated Mental Health Care' community-based approach influenced by the BFT model of Falloon and colleagues (F- BFT): needs assessment, psychoeducation, skills training.	General, Outpatient	Cross- sectional, Mixed Methods	11 CPNs, 7 community workers, 5 OTs, 3 SWs, 2 Managers, 1 Psychiatrist, 1 Psychiatric Registrar, 1 Activity Centre Coordinator, 1 Liaison Officer, 1 CP and 1 Therapist	a) Questionnaire (rating scale) b) Semi-structured interviews
UK (England), English, 2000 [64]	Book Chapter	To investigate how FI had been integrated into former 'Thorn Course' trainees' routine work, examine the nature of any difficulties and determine if it's possible to predict which trainees would be more able to implement FI skills acquired during training.	<b>Family Intervention</b> . 'Psychosocial Family Interventions for psychosis': formulation driven, cognitive behavioural family approach: needs assessment, education, skills training.	General, Inpatient & Outpatient	Cross- sectional, Mixed Methods	16 community-based, 2 ward-based MHNs, 2 managers, 1 lecturer	Questionnaire (rating scale & op ended responses)
UK (England), English, 2003 [65]	Journal Article	To examine the effectiveness of the 'FIRST' FI training programme and compare experiences of staff in Somerset with staff in previous studies.	<b>Family Intervention.</b> 'Psychosocial Family Interventions for psychosis' based on the 'S.T.E.P. Service' model: individual and family CBT with systemic perspective: needs assessment, education, skills training.	General, Inpatient & Outpatient	Cross- sectional, Mixed Methods	8 CPNs, 5 MHNs, 2 SWs, 1 Psychiatrist, 1 CP, 1 Art Therapist	<ul> <li>a) Questionnaire</li> <li>(rating scale &amp; ope</li> <li>ended responses)</li> <li>b) Focus groups</li> </ul>
India, English, 2012 [85]	Journal Article	To report on the researching, planning and delivery of a pilot of a community based intervention for people with schizophrenia and their carers, delivered by lay health workers.	<b>Family Intervention.</b> Community-based intervention for people with schizophrenia and their families: weekly home based sessions, needs assessment, psycho-education, adherence management, rehabilitation, health promotion.	General, Outpatient	Case Study	N/A	Descriptive accour
UK (England),	Un- published	To examine the experiences of trainers on the 'Meriden - West Midlands Family	Family Intervention. 'Meriden Family Work Programme' based on F-BFT. 10 to 14	General, Not	Cross- sectional	42 Behavioural Family Therapy Trainers	Structured written and phone

BMJ Open

2 3	English,	Audit	Programme' programme, including	sessions: psychoeducation, relapse planning,	Reported			questionnaires
4 5	2001 [66]	, addit	motivations, frustrations, benefits and support from being involved in Meriden.	skills training.	Reported			(open-ended responses)
6 7 8 9	UK (England), English, 1997 [67]	Journal Article	To establish the prevailing issues and working practices of qualified Mental Health Nurses carrying out FI.	<b>Family Intervention.</b> 'Schizophrenia Family Work', based on F-BFT principles: psychoeducation, problem solving, skills training.	General, Inpatient & Outpatient	Cross- sectional, Mixed methods	36 CPNs, 2 ward based MHNs	Questionnaire (rating & open- ended response)
10 11 12 13	United States, English, 2007 [68]	Journal Article	To discuss barriers to implementing FI in the treatment of psychotic-spectrum illnesses, in both inpatient and outpatient settings.	<b>Family Intervention.</b> 'Family focused evidence based treatment': psychoeducation, problem solving, skills training.	General, Inpatient & Outpatient	Case Study	N/A	a) Descriptive account b) Case study
14 15 16 17 18 19	UK (England), English, 1991 [69]	Journal Article	To describe the effect on the role and function of the Community Psychiatric Nurse after training to deliver psychosocial intervention to families caring for a relative with schizophrenia living at home.	<b>Family Intervention.</b> 'Psychosocial Intervention', based on F- BFT: needs assessment, psychoeducation, skills training, problem-solving, medication compliance, crisis planning, cognitive behavioural management strategies.	General, Outpatient	Cross- sectional	18 CPNs	Questionnaire (rating & open- ended response)
20 21 22 23 24 25	UK (Wales), English, 1991 [101]	Journal Article.	To investigate what carers found helpful and unhelpful about the community-based FI programme.	<b>Family Intervention.</b> Based on the 'S.T.E.P. Service' model of individual and family CBT with systemic perspective: psychoeducation; needs assessment for further FI: problem solving, behavioural goal setting, medication management, relapse management, skills training.	General, Outpatient	Cross- sectional, Qualitative	20 relatives of people with a diagnosis of schizophrenia or schizoaffective disorder	Semi-structured interviews
26 27 28 29 30	UK (Ireland), English, 2014 [83]	Journal Article	To investigate participants' use of PSI in clinical practice following postgraduate training.	<b>Family Intervention.</b> 'Psychosocial Intervention', based on F- BFT: needs assessment, psychoeducation, skills training, problem-solving, medication compliance, crisis planning, cognitive behavioural management strategies.	General, Inpatient & Outpatient	Cross- sectional	8 MHNs	Questionnaire (open-ended response)
31 32 33 34 35 36	UK (England), English, 2004 [89]	Journal Article	To describe the lived experiences of families who had received the family intervention of BFT.	<b>Family Intervention.</b> 'Meriden Family Work Programme' based on F-BFT: psychoeducation, skills training, relapse management, problem solving.	General, Outpatient	Cross- sectional, Qualitative	9 service users with a diagnosis of severe mental illness (schizophrenia, bipolar disorder, severe depression), 18 family members	Semi-structured family interviews
37 38 39 40 41 42 43 44	United States, English, 2010 [70]	Journal Article	To study the implementation of an FI in order to perform a process analysis of implementation and examine utilisation of the intervention.	<b>Family Intervention.</b> 'Psychoeducation & EQUIP (Enhancing Quality of Care in Psychosis)': family outreach, needs assessment and care coordination, medication management, and optional further family intervention.	Specialised (Veterans Affairs), Outpatient	Cross- sectional, Mixed methods	173 patients with a diagnosis of schizophrenia or schizoaffective disorder; 18 clinicians (Psychiatrists and Psychiatry Residents)	a) Questionnaire (ratings and open- ended responses) b) Semi-structured interviews.
45 46 47 48 49			For peer review o	only - http://bmjopen.bmj.com/site/abo	ut/guideline	s.xhtml		

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3 4 5	Spain, Spanish, 2011 [71]	Journal Article	To describe the implementation process of a family psychoeducation programme in nine mental health services in Spain.	<b>Family Intervention.</b> Based on F-BFT: psychoeducation, problem solving, skills training, relapse management.	General, Outpatient	Case Study	N/A	Descriptive account
6 7 8 9 10 11	Italy, Italian, 2011 [72]	Journal Article	To identify benefits and barriers in implementing a family psychoeducation programme, according to professionals perspectives and participation of families to the programme.	<b>Family Intervention.</b> Based on F-BFT: psychoeducation, problem solving, skills training, relapse management.	General, Outpatient	Cross- sectional, Mixed methods	10 psychiatrists, 5CPs, 6 MHNs and 1 rehabilitation therapist	a) Descriptive reports of attrition b) Questionnaire (ratings and open- ended responses).
12 13 14 15	UK (England), English, 2009 [84]	Book Chapter	To provide an organisational case analysis of implementing a new family services programme in one UK Trust.	<b>Family Intervention.</b> 'Meriden Family Work Programme' based on F-BFT: psychoeducation, skills training, relapse management, problem solving.	General, Inpatient & Outpatient	Case Study	N/A	Descriptive account
16 17 18 19	UK (England), English, 2002 [74]	Book Chapter	To describe strategic approach to the implementation of evidence-based approaches to family interventions in the UK West Midlands area.	Family Intervention. Based on the 'Meriden Family Work Programme' used by Fadden and colleagues: psychoeducation, skills training, relapse management, problem solving.	General, Inpatient & Outpatient	Case Study	N/A	Descriptive account
20 21 22 23 24	UK (England), English, 1997 [73]	Journal Article	To ascertain the extent to which therapists trained in BFT have used the skills in their day-to-day work, to examine what difficulties they had encountered and to define outcomes and factors related to success.	<b>Family Intervention.</b> Based on Fadden's 'Meriden Family Work Programme': psychoeducation, skills training, relapse management, problem solving.	General, Inpatient & Outpatient	Cross- sectional, Mixed methods	35 CPNs, 20 MHNs, 9 Psychiatrists, 8 OTs, 7 SWs, 7 Rehabilitation Officers	a) Questionnaire (Rating and open- ended responses) b) Between group comparison of ratings
25 26 27 28 29 30 31	UK (Scotland), English, 2004 [102]	Journal Article	To compare and contrast different elements of PSI courses and how they may impede/facilitate implementation , understand organisational catalysts/barriers and chart the relationship between organisation, educational and care arrangements on the use of PSI.	<b>Family Intervention.</b> 'Psychosocial Intervention', developed from F-BFT: assessment of relatives, psychoeducation, skills training, problem-solving, crisis management, cognitive behavioural management strategies.	General, Outpatient	Cross- sectional, Qualitative	3 Service Managers, 7 Lecturers, 16 Mental Health Workers	Semi-structured interviews
32 33 34 35 36	Canada, English, 2006 [75]	Journal Article	To compare family nursing interventions of nurses before and after an educational programme based on the Calgary Family Assessment Model and Calgary Family Intervention Model and to explore perceptions of the programme.	<b>Systemic Psychotherapy.</b> 'Family systems nursing approach': Targeting interactions between members of the family and between the family and practitioner.	General, Inpatient	Cross- sectional, Qualitative	7 MHNs	a) Content analysis of logbooks b) Semi-structured interviews
37 38 39 40	Australia, English, 2008 [86]	Conference Paper	To evaluate service implementation of the 'Building Family Skills Together Programme'.	<b>Family Intervention.</b> Based on Fadden's 'Meriden Family Work Programme': psychoeducation, skills training, relapse management, problem solving. 'Family Sensitive Practice' and a Family Practice	General, Outpatient	Case Study	N/A	Descriptive account
41 42 43	Germany,	Journal	To assess the feasibility of continuous	Consultant embedded in each service. Systemic Psychotherapy. A systemic	General,	Cross-	Staff trained in the	a)Questionnaire
43 44 45 46 47 48			For peer review o	nly - http://bmjopen.bmj.com/site/abo	ut/guideline	es.xhtml		

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3 4 5	English, 2013 [76]	Article	implementation of SYMPA (Systems therapy methods in acute psychiatry) related methods.	resource-oriented and solution-oriented psychotherapeutic treatment.	Inpatient	sectional	SYMPA method: survey 51, interviews 56 (overlap in participants)	(rating and open- ended responses) b) Semi-structured interviews
6 7 8 9 10 11	UK (England), English, 1978 [90]	Journal Article	To identify problems associated with implementing a behavioural intervention.	<b>Behavioural Therapy.</b> 'Behavioural Modification': Operant conditioning to reinforce "good" behaviours and discourage unhelpful ones, with the assistance of family members, needs assessment, information and individualised practical support and advice for families.	General, Outpatient	Case Study	N/A	Descriptive account
12 13 14 15 16	UK (Wales), English, 1996 [96]	Journal Article	To present an account of implementing FI within a routine clinical service rather than as part of a specially funded research project.	Family Intervention. Based on the 'S.T.E.P. Service' model: psychoeducation; needs assessment for further FI: problem solving, behavioural goal setting, medication management, relapse management, skills training.	Specialised (Family Intervention Service), Outpatient	Case Study & Audit report, Mixed methods	N/A	a) Descriptive account b) Audit results
17 18 19 20	UK (England), English, 2006 [95]	Journal Article	To establish what therapists and families believe to be helpful (or otherwise) in the engagement of families in Behavioural Family Therapy.	Family Intervention. F-BFT based model: needs assessment, psychoeducation, individual problem-solving approach, skills training.	Generic, Inpatient & Outpatient	Cross- sectional, Qualitative	2 MHNs, 1 OT, 1 CP, 1 Physiotherapist, 1 SW, 1 Nurse Manager; 7 relatives: 3 Mothers, 2 Fathers, 1 Step-father, 1 Daughter	Semi-structured interviews
21 22 23 24 25 26	Australia, English, 1993 [77]	Journal Article	To identify staff members' difficulties in applying the FI and to predict the systematic use of the intervention with families.	Family Intervention. 'Living with Schizophrenia' programme: needs assessment, interactive psychoeducation, relapse management, goal-setting, problem solving, cognitive-behavioural self-management.	General Outpatient	Cross- sectional, Quantitativ e	29 MHNs, 8 CPs, 2 OTs, 3 SWs, 2 psychiatric registrars and 1 psychiatrist	a) Questionnaire (ratings and examination of intervention knowledge) b) Regression analysis
27 28 29 30 31	UK (England), English, 2010 [87]	Journal Article	To evaluate a cross-educational practice meeting in assisting 'Thorn Course' graduates to implement PSI into clinical practice.	Family Intervention. 'Psychosocial Intervention' Thorn model, developed from F- BFT: assessment of relatives, psychoeducation, skills training, problem- solving, crisis management, cognitive behavioural management strategies.	General, Not Reported	Cross- sectional, Qualitative	8 Thorn graduates, 4 Line Managers, 2 Thorn lecturer practitioners, 1 operational services director	Semi-structured interviews
31 32 33 34 35 36 37	International (Greece, Germany, Italy, Portugal, Spain, UK), English, 2005 [78]	Journal Article	To investigate the implementation and effectiveness of a standard psychoeducational family intervention in six European countries, exploring feasibility, difficulties, benefits and impact.	<b>Family Intervention.</b> Based on F-BFT: psychoeducation, problem solving, skills training, relapse management.	General, Inpatient & Outpatient	Cross- sectional, Mixed methods	15 Psychiatrists, 14 MHNs, 7 CPs, 7 SWs, 1 OT, 4 other	Questionnaire (rating and open- ended responses)
38 39 40	Italy, English, 2006 [79]	Journal Article	To investigate feasibility of providing psychoeducational interventions for persons with schizophrenia and their families.	<b>Family Intervention.</b> Based on F-BFT: psychoeducation, problem solving, skills training, relapse management.	General, Outpatient	Cross- sectional, Mixed methods	15 Psychiatrists, 11 MHNs, 5 CPs, 4 Rehabilitation Therapists, 3 SWs	Questionnaire (rating and open- ended responses)
41 42 43 44	UK	Journal	To describe the use of the theory-based	Family Intervention. Psycho-education,	General,	Cross-	6 SWs, 5 MHNs, 4 Team	Semi-structured
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3 4 5 6	(England), English, 2007 [80]	Article	implementation interview (TBII) to understand the difficulties in implementing the family intervention recommendation within NICE's Schizophrenia guideline in three UK NHS Mental Health Trusts.	problem solving, crisis planning, and individualised patient interventions.	Outpatient	sectional, Qualitative	Managers, 3 CPs, 2 Psychiatrists	interviews
7 8 9 10 11	UK (England), English, 2013 [88]	Journal Article	To investigate trainee participant understanding of the use of family interventions in their clinical area, identify themes related to implementation into practice following completion of the module.	<b>Family Intervention.</b> Integration of F- BFT and family CBT models: needs assessment, use of behavioural interventions related to stress management and problem solving, relapse management.	General, Not Reported	Cross- sectional	5 trainees enrolled in the family intervention module	Semi-structured interviews
12 13 14 15	UK (England), English, 2007 [81]	Journal Article	To highlight issues encountered in service development and discuss development of the pilot project with a focus on why people who are trained in FI do not utilise the skills.	<b>Family Intervention.</b> Integration of F- BFT and family CBT models: needs assessment, use of behavioural interventions related to stress management and problem solving, relapse management.	General, Inpatient & Outpatient	Case Study & Cross- sectional, Qualitative	N/A	a) Descriptive account b) Focus groups
16 17 18 19	UK (Northern Ireland), English, 2008 [104]	Journal Article	To explore the roles and perspectives of mental health nurse practitioners towards clients with enduring mental illness and their carers following completion of PSI training.	Family Intervention. 'Psychosocial Intervention', developed from F-BFT: needs assessment, psychoeducation, skills training, problem-solving, relapse management, cognitive behavioural management strategies.	General, Inpatient & Outpatient	Cross- sectional, Qualitative	8 MHNs	Focus groups
20 21 22 23	UK (England), English, 2011 [82]	Journal Article	To examine the views of service users, relatives and care-coordinators of the value and barriers of involving family members in relapse prevention.	<b>Family Intervention.</b> 'Relapse Prevention Programme': six 1h manualised sessions; psychoeducation, relapse management, skills training, crisis intervention planning.	General, Outpatient	Cross- sectional, Qualitative	18 CPNs, 2 OTs, 1 SW; 21 individuals diagnosed with Bipolar Disorder; 10 relatives: 6 Spouses, 3 Parents, 1 Sibling	Semi-structured interviews
24 25 26 27 28 29	Finland, English, 2009 [100]	Journal Article	To determine how the participation of relatives in treatment was experienced by the relatives themselves, by the patients and by staff members and what the consequences of such participation were.	<b>Open Dialogue.</b> Rapid early involvement within 24 hours, as often as needed; meetings with any members of the patients' social network; collaborative participation of the patient and social network in every phase of decision making and treatment.	General, Outpatient	Cross- sectional, Qualitative	8 Psychiatrists, 5 CPs, 9 MHNs; 10 individuals diagnosed with Schizophrenia; 14 relatives: 4 Mothers, 1 Father, 3 Sisters, 1 Brother, 3 Spouses, 2 ex- Spouses, 1 Cousin	Semi-structured family interviews
30 31 32 33 34	Finland, English, 2004 [99]	Journal Article	To elucidate the experiences and importance of co-operation [in treatment] for the patients.	<b>Open Dialogue.</b> Rapid early involvement; social network meetings; collaborative decision making and treatment.	General, Outpatient	Cross- sectional, Qualitative	22 individuals receiving treatment: 9 Psychosis Spectrum Disorder; 6 Depressive or Anxiety Disorder; 7 Other mental disorder	Semi-structured interviews
35 36 37	Finland, English, 2006 [93]	Journal Article	To illustrate Open Dialogue treatment principles and process, with illustration from case studies, 5 years on from introduction.	<b>Open Dialogue.</b> Rapid early involvement; social network meetings; collaborative decision making and treatment.	General, Inpatient & Outpatient	Case Study	N/A	a) Descriptive account b) Case series
38 39	Finland, English, 2001 [91]	Journal Article	To illustrate Open Dialogue process treatment principles and process, with illustration from a case study.	<b>Open Dialogue.</b> Rapid early involvement; social network meetings; collaborative decision making and treatment.	General, Inpatient & Outpatient	Case Study	N/A	a) Descriptive account b) Case study
40 41 42 43 44	Finland, English, 2006 [94]	Journal Article	To illustrate Open Dialogue process treatment principles and process , using examples of poor and good outcome case	<b>Open Dialogue.</b> Rapid early involvement; social network meetings; collaborative decision making and treatment.	General, Inpatient & Outpatient	Case Study	N/A	a) Descriptive account b) Case series
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3 4 5 6	Finland, English, 1994 [97]	Journal Article	studies. To clarify the co-evolving process between the family and hospital and report some results using the Open Dialogue approach.	<b>Open Dialogue.</b> Rapid early involvement; social network meetings; collaborative decision making and treatment.	General, Inpatient & Outpatient	Case Study	N/A	a) Descriptive account b) Case study
7 8 9 10	UK (England), English, 2003 [92]	Journal Article	To evaluate the Family Support Service in terms of satisfaction, clinical outcome, investigating aspects families found helpful/unhelpful and other factors possibly linked with satisfaction/outcome.	<b>Family Intervention.</b> 'Psychosocial Family Interventions for psychosis' following 'FIRST course' training: individual and family CBT with systemic perspective: needs assessment, education, skills training.	Specialised (Family Support Service), Outpatient	Cross- Sectional, Qualitative	13 family interviews (23 individuals); Psychotic symptoms	Group interview
11 12 13 14 15 16	United States, English, 2000 [103]	Journal Article	To examine the relationship between independent observers' and therapists' ratings of difficulty in implementing family treatment for patients with bipolar disorder and pre-treatment measures of relatives' emotional attitudes (EE), affective behaviors during family interactions, and patients' residual symptoms.	<b>Family Intervention</b> . 'Family Psychoeducation' adapted from F-BFT: psychoeducation, communication training, problem-solving, relapse management and crisis intervention planning.	Generic, Inpatient	Cross- Sectional, Qualitative	26 individuals diagnosed with Bipolar Disorder; 33 relatives: 12 Mothers, 13 Fathers, 5 Spouses, 1 Aunt, 1 Cousin, 1 Grandmother	Semi-structured interviews
17 18 19 20 21	UK (England), English, 2005 [105]	Journal Article	To obtain feedback from couples and families on various aspects of the systemic therapy service and suggestions for service improvement.	Systemic Psychotherapy. Milan systemic and narrative based approaches.	Specialised (Systemic Therapy Service), Outpatient	Cross- Sectional, Mixed methods	25 couples and families receiving systemic therapy for psychotic, personality, anxiety and depressive disorders	a) Observation b) Clinical interviews c) Questionnaire (rating responses)
22 23 24			, Behavioural Family Therapy; <i>F-BFT</i> , Falloon's mc sychiatric Nurse ; <i>MHN</i> , Mental Health Nurse; <i>OT</i> , 6	odel of Behavioural Family Therapy; <i>CBT</i> , Cognitive Be Occupational Therapist; <i>SW</i> , Social Worker	-		· · ·	ogist;
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# PRISMA 2009 Checklist

Section/topic	#	Checklist item	Reported on page #
TITLE	-		
Title	1	Identify the report as a systematic review, meta-analysis, or both.	1
ABSTRACT	•	·	
2 Structured summary 3 4	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	2-3
Rationale	3	Describe the rationale for the review in the context of what is already known.	4-5
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	5
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	Protocol was uploaded as a supplementar file
3 Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	6
) Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	5-6
3 Search 4 5 7 8	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	5-6. Database search strategy was uploaded as a supplementary file.
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	5-7. Figure 1 (PRISMA flow Diagram)
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators. For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml	7-8

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# PRISMA 2009 Checklist

Data items	items 11 List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.			
Risk of bias in individual studies	5			
2 Summary measures 3 4	Summary measures 13 State the principal summary measures (e.g., risk ratio, difference in means).			
6 Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I <sup>2</sup> ) for each meta-analysis.	7 (Methods of analysis paragraph)	
9 20	•	Page 1 of 2		
2 Section/topic	#	Checklist item	Reported on page #	
4 Risk of bias across studies 5 6 27 28	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	N/A (See strengths and limitations, page 16)	
9 Additional analyses 0 1 1 22 33	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	N/A (See strengths and limitations, page 16)	
6 Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	Page 8 and Figure 1	
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	Page 8-9 and Supplemetary Table 1	

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# PRISMA 2009 Checklist

	00		
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	N/A (Data analysed using a theoretical thematic analysis approach)
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	N/A (Data analysed using a theoretical thematic analysis approach)
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	N/A (See strengths and limitations, page 16)
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	N/A (See strengths and limitations, page 16)
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	14-15, 16-17
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	15-16
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	16-18
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	18

46 From: Moher D, Liberati A, Tetzlaff J, Altman DG, The BRISMA General Science (2009) Proferred (Bengeing Henry for Switching Beviews and Meta-Applying: The PRISMA Statement. PLoS Med 6(6): e1000097. 47 doi:10.1371/journal.pmed1000097

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# Implementing family involvement in the treatment of patients with psychosis: a systematic review of facilitating and hindering factors.

Journal:	BMJ Open
Manuscript ID:	bmjopen-2014-006108.R1
Article Type:	Research
Date Submitted by the Author:	20-Aug-2014
Complete List of Authors:	Eassom, Erica; Queen Mary University of London, Unit for Social and Community Psychiatry Giacco, Domenico; Queen Mary University of London, Unit for Social and Community Psychiatry Dirik, Aysegul; Queen Mary University of London, Unit for Social and Community Psychiatry Priebe, Stefan; Queen Mary University of London, Unit for Social and Community Psychiatry
<b>Primary Subject Heading</b> :	Mental health
Secondary Subject Heading:	Mental health, Communication, Evidence based practice
Keywords:	Schizophrenia & psychotic disorders < PSYCHIATRY, Health policy < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, Organisational development < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, Quality in health care < HEALTH SERVICES ADMINISTRATION & MANAGEMENT

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# TITLE PAGE

'Implementing family involvement in the treatment of patients with psychosis: a systematic

review of facilitating and hindering factors'

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#### ABSTRACT

# **Objective:**

To synthesise the evidence on implementing family involvement in the treatment of patients with psychosis with a focus on barriers, problems and facilitating factors.

#### Design:

Systematic review of studies evaluating the involvement of families in tripartite communication between health professionals, 'families' (or other unpaid carers) and adult patients, in a single-family context. A theoretical thematic analysis approach and thematic synthesis were used.

#### Data sources:

A systematic electronic search was carried out in seven databases, using database specific search strategies and controlled vocabulary. A secondary hand search of grey literature was performed as well as using forwards and backwards snowballing techniques.

# **Results:**

A total of 43 studies were included. The majority featured qualitative data (n=42), focused solely on staff perspectives (n=32) and were carried out in the United Kingdom (n=23). Facilitating the training and ongoing supervision needs of staff are necessary but not sufficient conditions for a consistent involvement of families. Organisational cultures and paradigms can work to limit family involvement, and effective implementation appears to operate via a whole team co-ordinated effort at every level of the organisation, supported by strong leadership. Reservations about family involvement regarding power relations, fear of negative outcomes and the need for an exclusive patient-professional relationship may be explored and addressed through mutually trusting relationships.

## **Conclusions:**

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Implementing family involvement carries additional challenges beyond those generally associated with translating research to practice. Implementation may require a cultural and organisational shift towards working with families. Family work can only be implemented if this is considered a shared goal of all members of a clinical team and/or mental health service, including the leaders of the organisation. This may imply a change in the ethos and practices of clinical teams, as well as the establishment of working routines that facilitate family involvement approaches.

# **Strengths and Limitations**

Our study:

- Can inform policies and guidelines on family involvement so that they impact on routine practice.
- Is novel in covering a wide range of family involvement practices, highlighting common barriers, problems and facilitating factors.
- Synthesises rich qualitative data from professionals, patients and families.
- Could not include subgroup and quality analyses, due to the high correspondence between type of family involvement practice and methodology.
- May be conceptually limited as extant research has focused on perspectives of staff involved in family work and few studies are available on families' views.

#### Key words:

Carers; Psychosis; Severe mental illness (SMI); Family Intervention (FI); Implementation

Word count: 4,939 (excluding title page, abstract, references, figures and tables)

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#### BACKGROUND

The process of deinstitutionalisation of mental health care in the western world has led to families and others in the community shouldering the psychosocial burden of care and informally adopting the role previously provided by professionals in health care services [1-3]. The adoption of protected terms such as 'carer' in the United Kingdom (UK) and 'caregiver' in the United States (US) is a response to the substantial, yet 'nonprofessional' role that individuals in a close relationship have in supporting a person receiving mental health treatment. The term may include parents, partners, siblings, children, friends or other people significant to the individual: essentially, anyone who provides substantial support without being paid. The term carer can be problematic, being considered by some to have connotations of dependency and of minimising the significance of the relationship [4]. Also, many 'carers' do not self-identify as such, and consider their caring role as being within the traditional responsibilities expected of them. To avoid confusion when referring to family-directed initiatives, the single term 'families' will be adopted throughout this review, and broadly applies to a person's social network, not excluding their non-blood relatives.

'Family involvement' in mental health services can take different forms, depending on the level of need and availability of services. Generally, it can be conceived on a spectrum from more basic functions to specialised interventions, the minimal level including the provision of general information on the mental health service and assessments. On a more complex and specialised level, services can offer families psychoeducation, consultation, Family Interventions (FIs) and therapies [5]. There are both strong economic and moral imperatives to establish meaningful involvement and true collaborative working between families and health professionals. These are recognised by international government policies and psychiatric guidelines stipulating that families should be supported and actively involved in psychiatric treatment [6-11]. Families can encourage engagement with treatment plans, recognise and respond to early warning signs of relapse [12] and assist in accessing services during period of crisis [13-15]. Family involvement can lead to better outcomes from psychological therapies [16] and pharmacological treatments [17], fewer inpatient admissions, shorter inpatient stays, and better quality of life reports by patients [18-21].

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However, despite the vast evidence base for Family Intervention [22-28] and Family Psychoeducation [29], evidence suggests that family involvement is often not implemented in routine mental health care. There is an abundance of both quantitative and qualitative studies into experiences of inpatient care reporting that families feel marginalised and distanced from the care planning process. Common themes across international studies indicate that families feel isolated, uninformed, lack a recognised role and are not listened to or taken seriously [1, 30-43]. Families also commonly report feeling that confidentiality is used by professionals as a way to not share information [39, 44]. Family Intervention as a treatment approach is startlingly under-implemented, with extremely low numbers of families actually receiving it in clinical services [11, 45-47]. It is the case that for many, contact between professionals and families remains limited to telephone calls during crisis periods [48].

Why is family involvement in treatment so under-applied? There has been much debate about the reasons (e.g. [22, 49-51]) and some suggest they are linked to general problems of implementing new evidencebased practices in clinical services [29]. Other proposed barriers are more specific to family interventions, such as the danger of increasing burden related to caregiving, role strain, lack of experience and/or interest [52] and the complexities of navigating confidentiality [53]. Such discussions are largely speculative and reviews of evidence tend to focus on the provision of specific interventions, such as Family Psychoeducation [29] or Family Intervention [54]. This systematic review aims to assess how the involvement of families is implemented in the treatment of patients with psychosis, taking a broad view of involvement as described above in order to capture the barriers, problems and facilitating factors that operate in practice. In doing so, this may help to better define and implement families' involvement in psychiatric treatment in the future.

#### **METHODS**

The full protocol for this systematic review is reported in the Supplementary file 1.

# Identifying relevant studies

Computerised databases were searched for eligible studies: MEDLINE, EMBASE, PsycINFO, AMED (via Ovid), BNI and CINAHL (via HILO), Social Sciences Citations Index (via Web of Knowledge) and CDSR, DARE and CENTRAL (via the Cochrane Library). Word groups representing patient diagnosis, intervention and involvement terms and outcome descriptors were combined in several ways. Strategies were adapted for each database, using controlled vocabulary (MeSH, Emtree, Thesaurus of Psychological Index Terms) and free text (see Supplementary File 2). The search was last repeated on 01/06/2014.

Publication bias was minimised by including conference papers and book chapters, searching grey literature for dissertations and reports (ETHOS, SIGL) and corresponding with authors to identify further works. Both backward snowballing (from the reference lists of included studies and identified reviews) and forward snowballing (finding citations to the papers) was conducted.

# **Inclusion procedure**

A study was eligible for inclusion if: 1) it was an original collection of data; 2) situated in primary or secondary mental health services; 3) the patient population included people being treated for psychotic disorders<sup>1</sup>; 4) the intervention involved tripartite communication between health professionals (any), families (unpaid carers) and adult patients, excluding those focused exclusively on professional–family communication, family-family communication or multiple-family groups; and 5) results described barriers, problems and/or facilitating factors in involving families in treatment. No study type was excluded, however only Latin-script languages were able to be translated.

'Barriers' were defined as factors that prevented an approach from taking place or limited the scope of it, 'problems' referred to issues that emerged when delivering an approach and 'facilitating factors' were considered to be any factors that aided implementation or delivery. 'Family involvement' was defined inclusively as any process allowing health professionals, families and patients to actively collaborate in treatment, such as in making joint treatment decisions. Studies not reporting clear information on how

<sup>&</sup>lt;sup>1</sup> Attempts were made where possible to focus on patients with psychosis, however many studies used opportunity sampling of mixed 'severe mental illness' groups, which were included in order to be as inclusive as possible.

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families were involved in treatment were excluded. Studies into general experiences, opinions, satisfaction or needs were also excluded, unless they related to a clearly described specific involvement in treatment.

Two reviewers (EE and DG) screened all of the titles and collected relevant abstracts. These were screened and then excluded if they did not fit the selection criteria. Studies that seemed to include relevant data or information were retrieved and their full text versions analysed and examined for study eligibility. All final full text choices were confirmed and agreed by both reviewers.

# Method of Analysis

Data extraction and synthesis was guided by the *Economic and Social Research Council (ESRC)*'s Guidance on the Conduct of Narrative Synthesis in Systematic Reviews [55].

The included studies used both qualitative and quantitative methods, yet clearly had conceptual overlaps despite reporting results in different formats. Any available quantitative data were usually descriptive, reported in addition to qualitative findings and were largely used to explore existing themes or concepts. It was therefore considered appropriate to transform quantitative findings into qualitative form to systematically identify the main concepts across the studies using thematic analysis [55 , 56]. The use of this method is increasingly being advocated with studies involving data that are quantitative or from mixed methods [56-58] to address questions relating to intervention need, appropriateness and acceptability in systematic reviews [59].

# **Data extraction and synthesis**

Theoretical Thematic Analysis [60] using inductive themes to identify the barriers, problems and facilitating factors of family involvement was used as a framework to explore further themes.

Two non-clinician researchers (EE and AD) independently extracted author interpretations and participant data from the included studies using a piloted data extraction sheet. They then separately allocated the findings to relevant sections of the framework (e.g. 'Barriers according to staff perspectives') and coded the data within each section. Identified categories (e.g. 'Unsupportive attitudes of managers') were aggregated into subthemes (e.g. 'Attitudes towards family work') and finally became grouped under overarching themes (e.g. 'Context: Addressing Organisational Culture'). These emerging themes were discussed throughout analysis along with a clinician-researcher (DG), and discrepancies were resolved through iterative discussions. Robustness of the synthesis was investigated and themes were checked for completeness. Two clinician-researchers (DG and SP) acted as third party assessors of the final data synthesis.

#### RESULTS

# **Included studies**

Database searching produced 15615 titles to screen. After removing duplicates and irrelevant papers, a full text assessment of 119 documents was conducted. Twenty eight publications met our inclusion criteria and second stage searching including grey literature searching, personal correspondence and snowballing techniques led to the further identification and inclusion of 15 articles. This brought the final number of studies to 43. The PRISMA flowchart in Figure 1 depicts the identification and exclusion of articles. (Insert Figure 1 here).

## **Overview of papers**

Forty-two papers were published between 1991-2013 and one in 1978. Just over half of the studies were based on UK findings, with the rest from Finland, the USA, Italy, Australia, Canada, Germany, India, Ireland, New Zealand, Spain, Greece and Portugal. Mainly, papers reported on experiences of implementing Family Intervention approaches (n=33). Typically these followed a similar structure and were broadly modelled on the Behavioural Family Therapy approach [61] (see Supplementary File 3 for full study characteristics). This included variations such as 'Psychosocial Intervention' and 'Family Psychoeducation'

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that fit the model of a Family Intervention. The remainder explored Open Dialogue approaches (n=6), Systemic Psychotherapy (n=3) and one purely Behavioural Therapy programme. The vast majority were cross-sectional studies and 13 were naturalistic evaluations, descriptions or case studies of a service. In all, 37 papers explored staff perspectives, eight papers featured patient perspectives and six featured 'family' perspectives. In total, the review included data of 588 professionals, 321 patients and 276 'family members' or 'families'.

## In depth review: Synthesis across studies

Figure 2 summarises the final cross-study synthesis: the identified barriers/problems (in red) and facilitating factors (in green) and the themes in which they seemed to be operating. The themes closely relate to temporal sequencing in the process of delivering an intervention: the *context, engagement*, and then *delivery*. The figure provides a visual representation of the matches and gaps between barriers and facilitating factors related to involving families. This is for the most part conceptual, as barriers and their direct facilitating factors may not have been discussed in the same study. The themes and sub-themes are explored in greater detail in the synthesis below, which includes details of problems associated with delivering approaches that involve families as well as barriers and facilitating factors of this work.

(Insert Figure 2 here)

#### Context: Addressing the Organisational Culture

This theme reflects the majority of the findings, mostly from staff perspectives. Their experience of implementing family work could be characterised as working in relative isolation in a system where colleagues and managers did not value and prioritise family involvement or were openly hostile to it. With multi-disciplinary co-operation and working systems not in place, practical burdens associated with family

work were sometimes insurmountable. Mirroring this, factors that enabled family involvement to take place were related to top-down management support, prioritisation and changing the culture of family work.

# Organisational Attitudes and Paradigms

This subtheme covered general attitudes, such as family involvement not being valued at organisational and team level but also highlighted possible entrenched reasons for this. For example, individualistic, biological paradigms made family work seem secondary or optional [62-64] and staff found it difficult to adopt a collaborative stance, relinquishing the role of didactic problem solver [63]. In some cases, it appeared that historical negative attitudes towards families had not shifted [62, 64]. Anti-family work attitudes described amongst colleagues ranged from resistance towards the approaches [63, 65-68] to well-intentioned but complicating beliefs regarding clinicians' duty towards the patient [64, 69, 70]. Facilitating factors related not only to specific strategies but to an overall shared culture and prioritisation of family work [64, 71, 72], shifting attitudes towards viewing the family as equal partners [71, 73] and thinking more systemically about problems [71, 74].

# Practical Needs Associated with Family Work

Overwhelmingly, staff reported on the practical burdens of family work: that it requires time, resources and funding and is difficult to integrate with other clinical casework [62, 64-70, 73, 75-87], particularly in areas with high demands and clinical crises [73, 82, 83]. Specific needs reported for family work included flexible hours [64, 65, 67, 70, 80, 82-84, 87-90] and the accommodation of family requirements such as childcare facilities [80] or home visits [82, 89, 91]. A lack of systems and structure for carrying out and recording family work was also reported as a barrier to implementation and problem during delivery [63, 87, 92]. This included a lack of co-ordination between inpatient and outpatient care [62]. These issues were compounded by reports of services and managers not making time allowances for family work, e.g. not providing time in lieu for out of hours work [64, 65, 77, 83, 84], or obstructing time use, e.g. by refusing the release of staff for training [63].

# Management Culture

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Commonly, staff reported on the unsupportive attitudes of managers and colleagues as limiting the implementation of family involvement [63, 64, 66, 77-79, 87, 92, 93]. This ranged from a "*management culture of benign neglect rather than of active opposition*" [93] to overt challenges such as not respecting ring-fenced time for family work [87]. The strongest facilitator seemed to be that of strong leadership through senior management support and developing strategic solutions. This "sanctioned" family work, giving it core priority status within the service [64], and could facilitate specific powerful initiatives such as writing family work into business plans, policies and job descriptions of all staff [63, 79]. Further endorsement came from providing flexible hours, creating new staff roles and financial provision [63, 73, 79, 94]. The value emerged of having regular multi-disciplinary meetings to address team-specific needs [72, 78, 79, 88] and developing strategies that prioritised family work and made it a part of regular clinical practice [63, 72, 73, 79, 88, 94]. This included having routine assessment of all families, asking clinicians about families when reviewing caseloads and providing regular feedback of family data to teams and managers [63, 94].

# Training Needs

Staff also reported on lacking access to adequate supervision and training [62, 63, 65, 66, 83, 86, 87, 92] as barriers to implementation. This may link with reports of staff lacking skills or confidence to do the work [62, 64, 85, 86, 92]. Some problems during delivery (such as managing family dynamics [64, 65, 70, 74, 78, 88, 95]) could also be related to staff skills and experience [71, 78, 81]. As expected, having a structured regime of supervision, encouraging attendance and ongoing support was described as helping staff to deliver work with families [63, 72, 78, 79, 88]. Staff also reported on the value of belief in the approach and having an identity in their role [71, 72, 79, 81, 86].

### Team Attitudes, Commitment and Multi-disciplinary Co-operation

Difficulties arose when only a minority of team members had been trained in an intervention [82]. Staff reported that collaboration was often lacking [63, 65, 69, 73, 77, 80] and that involving families requires whole team commitment [76, 82]. 'Ownership' was sometimes an issue, with various staff groups

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perceiving family work as within the domain of other roles, not theirs [69, 80]. Role and team-specific issues also emerged, such as psychiatrists, inpatient staff and home treatment teams being less involved [63, 66, 73, 81]. Collaboration in the form of multi-disciplinary co-working, peer-supervision and whole team approaches were all reported as aids to implementing family work [63, 66, 71-74, 78, 79, 82, 88].

Problems with finding 'appropriate' referrals were reported widely [65, 67, 68, 77, 78, 80, 82, 83, 93]. Whilst some patients do not have families, the pervasiveness of this response also called into question staff members' pre-existing ideas about what constitutes an 'appropriate' family for intervention. Staff reported the resistance of other professionals to make referrals [67, 88], family work services being "forgotten" and referrals being made as a "last resort", by which time the families themselves may have grown resistant [93]. Acting as a facilitator was the promotion of family work, both as a cascading effect through colleagues and across services [64, 79, 87].

# Engagement: Addressing Concerns through Openness, Encouragement and Building Alliances

The next theme related to the process of engagement, informed more broadly by both staff and family responses. A picture emerged of families sometimes being reluctant to engage, and of valid concerns. Yet the successful establishment of trusting relationships indicates these concerns may be surmountable in many cases.

#### Reservations about Involving Families

Similar issues around the nature of involving families emerged as a barrier to families becoming involved and as problems during treatment. Some concerns seemed linked to fears around power and control: bidirectional privacy concerns (keeping the extent of the illness from the family and keeping family issues from services) [70] and patients' fears of placing relatives in a position of power [70, 95] or of exposing their vulnerability [75]. Responses in all three participant groups addressed the need for an exclusive patient-

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professional relationship [69, 70, 76, 95]. Existing individual and family problems (such as patients' symptoms being directed at family members [62]) also precluded family involvement. Both families and staff expressed fears of making the current situation worse, such as by burdening the family and worsening the patient's symptoms [70, 80, 84, 86, 91]. Professionals described building trust and rapport, through open discussions with the family, acknowledging concerns and providing reassurance [71, 74, 88, 91].

# Problems Engaging Families

These were often unspecified as scepticism, lack of motivation or refusal from the families, occurring prior to engagement or during treatment [65, 76, 78, 83, 84, 88, 93, 96]. As professional responses, these may reflect their attitudes towards families as unmotivated, but could also describe the failure of the team to mobilise the family in favour of treatment [96]. A factor described as a facilitator was having a critical period of engagement: intensive efforts at contact and involvement early on after contact with services [93, 96-99] and presenting the approach enthusiastically [71, 89] functioned to establish collaborative relationships between families and professionals as the modus operandi.

# Delivery: Active Collaboration, Professional Skills and Respect for Families as Individuals

The final theme related to factors that affected how staff members delivered family interventions and how families experienced them. As a whole, both family and staff responses highlight the importance of respectful, equal partnership, enhanced by professional skills and experience.

## Working Relationships between Families and Professionals

Collaboration between families and professionals on an equal footing appeared valued by both families and professionals. Lack of collaboration was cited as a problem during delivery, resulting in families feeling patronised or not understood [76]. Open Dialogue papers particularly emphasised the lack of success when actions were unilaterally decided, rather than emerging from a joint process [74, 99]. Factors helping to overcome this included being able to relinquish control, i.e. tolerate uncertainty in order to allow a joint

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solution to emerge [78, 96, 98-100], approaching the family on an equal basis [71] and actively collaborating with families during meetings [66, 71, 89, 92, 96].

How families experienced an approach closely linked with their experience of the professional. Some families reported experiencing an approach as negative or critical, both through the model itself e.g. its characterisation of illness [101], or experiences of the professional, perhaps as criticising parenting [101, 102]. Yet, the interpersonal qualities of the professional and the establishment of a therapeutic alliance strongly emerged as facilitating factors: professionals being informed, genuine, warm, non-blaming [71, 89, 101] and demonstrating an awareness and understanding of the problems of the whole family [71, 79, 89, 90, 99].

A lack of continuity was cited as a problem [99], whilst a facilitator was having the same team involved from the beginning and staying with the family throughout the treatment process [96, 98, 99].

# Individualisation within the approach

Approaches were sometimes described as culturally insensitive [76, 88]: rigid, manualised approaches did not meet the general needs of particular groups whilst individual needs, such as illiteracy, were sometimes not catered to [64, 76, 97, 103]. Professionals and families valued having a clear structure whilst allowing for flexibility [71, 76, 88, 99]. Professionals' skills were also important, by way of communicating information in an easy-to-understand format, avoiding jargon [71, 88, 89, 99] and developing an individualised and contextualised approach [71, 76, 88, 93, 99].

# Working with Complex Needs

Professionals highlighted the complexities of working both with families and with patients with psychosis. The difficulties of managing patient symptoms and working in a meaningful way with their beliefs [73, 104] may be compounded by family dynamics [64, 65, 70, 74, 78, 88, 95, 104] and potentially relatives' own emotional and affective problems [104]. Staff members' qualities, skills and experience in the area

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were naturally described as facilitating factors [71, 76, 78, 79, 81, 83, 89, 90, 100]. Perhaps unsurprisingly, useful skills were described as working creatively to overcome barriers, hypothesising, reflecting and persevering [71, 79, 100].

#### DISCUSSION

# Main findings

Our results suggest that having 'top-down' support and training some staff members to carry out family work is necessary but not sufficient. In order to effectively implement family involvement in care, all members of a clinical team should be trained and regularly supervised and a 'whole team approach' should be used. Developing a clear structure for the intervention may be beneficial for the delivery of family involvement, provided that flexibility to accommodate individual needs is ensured. Concerns emerged regarding privacy, power relations, fear of negative outcomes and the need for an exclusive patientprofessional relationship. Exploring and acknowledging such concerns through open, yet non-judgemental communication could facilitate the establishment of a therapeutic alliance between staff, families and patients.

These findings may help to explain why family interventions – despite their overwhelming evidence base and their inclusion in practically all policies and guidelines – are so poorly implemented in routine practice. The requirements identified may be challenging given that family-oriented practice may need to be embraced by a whole organisation and included in work routines in order to be implemented.

## **Strengths and limitations**

To our knowledge, this is the first systematic review that specifically focused on barriers, problems and facilitating factors for the implementation of family involvement in the treatment of patients with psychosis. This is of high importance given the current climate of government policies and psychiatric guidelines stipulating that families should be supported and actively involved in psychiatric treatment [6-11], and the

disappointments in achieving this in practice so far. The search strategy allowed for the capture of a large number of studies, different researchers independently extracted and reviewed the data and when necessary authors were contacted to clarify ambiguous information. The use of thematic analysis, described as having the "most potential for hypothesis generation" [108], allowed for understanding the larger picture, which is more than the sum of its findings. Whilst interpretative, this process has been carried out in accordance with RATS guidelines [61] and presented transparently. Though some themes were not highly recurrent -for example criticisms of manualisation emerged only in structured approaches such as Behavioural Family Therapy- in all, findings were complimentary, not contradictory. The fact that common themes emerged in spite of variations in approach, across 16 countries, speaks for the robustness of the findings as representing shared issues with family involvement.

However a number of limitations must be considered when interpreting the results of this study. Methodologically, conducting sub-group analysis, i.e. for different intervention models, was not considered viable due to the strong association between type of approach and methodology used e.g. Open Dialogue with case studies and Behavioural Family Therapy with the Family Intervention Schedule (FIS) questionnaire. Carrying out a sub-group analysis may have therefore had the risk of mischaracterising certain approaches due to variation in the richness of data. Whilst there are well-established methods for assessing the quality of intervention studies, this is not the case for studies of implementation processes, qualitative or mixed methods research [56] and the use of appraisal tools in qualitative research remains contentious [109, 110]. The decision not to use quality-based analysis was therefore also based on recognition of the important contribution and explanatory value that descriptive accounts offer. Despite efforts to find grey literature, the search strategy may still have been limited in its bias towards published research, yet the nature of this review topic means that service level audits and evaluations are likely to be of relevance. Conceptually, the dominance of staff and academic perspectives may have led to barriers within the organisation being explored most thoroughly, however does not lead to the conclusion that there are no inherent problems with involving families in clinical settings.

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# Comparison with available literature and implications for practice

Our findings reflect important key features for implementation of evidence based practices, already identified in previous research in implementation science, such as top-down input and leadership and the need for continuing consultation and training [105]. The presence of management and leadership decisions and strategies operating as barriers and facilitating factors throughout the organisational context –both directly and indirectly– aligns with findings that leadership at all levels (e.g. executive director, middle manager, clinical supervisor) is associated with innovation [106], implementation of evidence based practice (EBP) [107], and with improving the organisational context for EBP implementation [108]. The need for support from senior managers (and commissioners) and for a whole team approach is also reflected in the suggestions on how to implement family work in mental health services provided by professionals and carers with experience of participating in a Family Behavioural Therapy Programme, [109].

The fundamental role of the organisational context is emphasised in the literature with both culture (the normative beliefs and shared expectations of the organisation) and organisational climate (the psychological impact of the work environment on the professional) strongly moderating the uptake of evidence based practices [110]. The practice to be implemented must match the mission, values, tasks and duties of the organisation and individuals within that organisation [111]. The absence of a strong organisational culture favouring family work may be influenced by traditional paradigms based on the predominance of biological models of mental illness, which tend to minimise the focus on the individual's social context [50]. Also, the characterisations of families as dysfunctional and sometimes even as 'the cause of psychiatric illness,' despite being widely rejected [112], may have contributed to a loss of trust in services and strained relationships between professionals and families [113]. This may explain the importance and the effort required in building alliances, which emerged in our findings. Clinicians may uphold the patient-professional alliance by addressing concerns regarding privacy and by being mindful that patients do not perceive a loss of power due to having family involvement in their care.

# **Future directions for research**

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So far the findings largely reflect what can go wrong rather than provide evidence of successful implementation. For example, sustainability has not been addressed in the review as this stage has hardly been reached. More research will be needed to see which organisational steps can actually change the culture in a service so that family involvement happens, not only in a research study or with particular patients, but with all families, every day, and over longer periods of time.

Future studies should attempt to better capture wider views, particularly in-depth understanding of patients' and families' views. This may also enable insight into the potentially varied experiences of minority groups. These views may be best obtained outside of group interviews, in which a power imbalance may be present. There would also be value in exploring the views of professionals who have not already demonstrated commitment to family work.

Despite a 'whole team approach' seeming to be the way forward for a widespread implementation of family work, there is a need to obtain insight into the organisational challenges that may be related to this and to develop clear practical guidelines for the reorganisation of clinical teams.

**Funding:** This paper presents independent research and was partially funded by the National Institute for Health (NIHR) Research Collaboration for Leadership in Applied Health Research and Care (CLAHRC) North Thames at Bart's Health NHS Trust. The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health.

Competing interests: The authors declare they have no competing interests.

Authors' contributions: DG, EE and SP contributed to the conception and design of the study. EE designed and conducted the search, DG and EE selected the studies. AD and EE extracted data and carried out the thematic synthesis. EE wrote the manuscript, AD and DG reviewed and edited the manuscript and SP provided critical review of the manuscript. All authors contributed to and approved the final submitted version.

Acknowledgements: None

Data Sharing Statements: No additional data available

# Figures & Table Legends

Figure 1. PRISMA flow diagram for paper selection

Figure 2. Barriers, problems and facilitating factors related to family work. Summary of themes

Supplementary File 1. Protocol for Systematic Review

Supplementary File 2. Modified database search strategies

Supplementary File 3. Characteristics of included studies (n=43)

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# TITLE PAGE

'Implementing family involvement in the treatment of patients with psychosis: a systematic

review of facilitating and hindering factors'

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#### ABSTRACT

# **Objective:**

To synthesise the evidence on implementing family involvement in the treatment of patients with psychosis with a focus on barriers, problems and facilitating factors.

#### **Design:**

Systematic review of studies evaluating the involvement of families in tripartite communication between health professionals, 'families' (or other unpaid carers) and adult patients, in a single-family context. A theoretical thematic analysis approach and thematic synthesis were used.

#### Data sources:

A systematic electronic search was carried out in seven databases, using database specific search strategies and controlled vocabulary. A secondary hand search of grey literature was performed as well as using forwards and backwards snowballing techniques.

# **Results:**

A total of 43 studies were included. The majority featured qualitative data (n=42), focused solely on staff perspectives (n=32) and were carried out in the United Kingdom (n=23). Facilitating the training and ongoing supervision needs of staff are necessary but not sufficient conditions for a consistent involvement of families. Organisational cultures and paradigms can work to limit family involvement, and effective implementation appears to operate via a whole team co-ordinated effort at every level of the organisation, supported by strong leadership. Reservations about family involvement regarding power relations, fear of negative outcomes and the need for an exclusive patient-professional relationship may be explored and addressed through mutually trusting relationships.

# **Conclusions:**

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Implementing family involvement carries additional challenges beyond those generally associated with translating research to practice. Implementation may require a cultural and organisational shift towards working with families. Family work can only be implemented if this is considered a shared goal of all members of a clinical team and/or mental health service, including the leaders of the organisation. This may imply a change in the ethos and practices of clinical teams, as well as the establishment of working routines that facilitate family involvement approaches.

# **Strengths and Limitations**

Our study:

- Can inform policies and guidelines on family involvement so that they impact on routine practice.
- Is novel in covering a wide range of family involvement practices, highlighting common barriers, problems and facilitating factors.
- Synthesises rich qualitative data from professionals, patients and families.
- Could not include subgroup and quality analyses, due to the high correspondence between type of family involvement practice and methodology.
- May be conceptually limited as extant research has focused on perspectives of staff involved in family work and few studies are available on families' views.

#### Key words:

Carers; Psychosis; Severe mental illness (SMI); Family Intervention (FI); Implementation

Word count: 4,939 (excluding title page, abstract, references, figures and tables)

The process of deinstitutionalisation of mental health care in the western world has led to families and others in the community shouldering the psychosocial burden of care and informally adopting the role previously provided by professionals in health care services [1-3]. The adoption of protected terms such as 'carer' in the United Kingdom (UK) and 'caregiver' in the United States (US) is a response to the substantial, yet 'nonprofessional' role that individuals in a close relationship have in supporting a person receiving mental health treatment. The term may include parents, partners, siblings, children, friends or other people significant to the individual: essentially, anyone who provides substantial support without being paid. The term carer can be problematic, being considered by some to have connotations of dependency and of minimising the significance of the relationship [4]. Also, many 'carers' do not self-identify as such, and consider their caring role as being within the traditional responsibilities expected of them. To avoid confusion when referring to family-directed initiatives, the single term 'families' will be adopted throughout this review, and broadly applies to a person's social network, not excluding their non-blood relatives.

'Family involvement' in mental health services can take different forms, depending on the level of need and availability of services. Generally, it can be conceived on a spectrum from more basic functions to specialised interventions, the minimal level including the provision of general information on the mental health service and assessments. On a more complex and specialised level, services can offer families psychoeducation, consultation, Family Interventions (FIs) and therapies [5]. There are both strong economic and moral imperatives to establish meaningful involvement and true collaborative working between families and health professionals. These are recognised by international government policies and psychiatric guidelines stipulating that families should be supported and actively involved in psychiatric treatment [6-11]. Families can encourage engagement with treatment plans, recognise and respond to early warning signs of relapse [12] and assist in accessing services during period of crisis [13-15]. Family involvement can lead to better outcomes from psychological therapies [16] and pharmacological treatments [17], fewer inpatient admissions, shorter inpatient stays, and better quality of life reports by patients [18-21].

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However, despite the vast evidence base for Family Intervention [22-28] and Family Psychoeducation [29], evidence suggests that family involvement is often not implemented in routine mental health care. There is an abundance of both quantitative and qualitative studies into experiences of inpatient care reporting that families feel marginalised and distanced from the care planning process. Common themes across international studies indicate that families feel isolated, uninformed, lack a recognised role and are not listened to or taken seriously [1, 30-43]. Families also commonly report feeling that confidentiality is used by professionals as a way to not share information [39, 44]. Family Intervention as a treatment approach is startlingly under-implemented, with extremely low numbers of families actually receiving it in clinical services [11, 45-47]. It is the case that for many, contact between professionals and families remains limited to telephone calls during crisis periods [48].

Why is family involvement in treatment so under-applied? There has been much debate about the reasons (e.g. [22, 49-51]) and some suggest they are linked to general problems of implementing new evidencebased practices in clinical services [29]. Other proposed barriers are more specific to family interventions, such as the danger of increasing burden related to caregiving, role strain, lack of experience and/or interest [52] and the complexities of navigating confidentiality [53]. Such discussions are largely speculative and reviews of evidence tend to focus on the provision of specific interventions, such as Family Psychoeducation [29] or Family Intervention [54]. This systematic review aims to assess how the involvement of families is implemented in the treatment of patients with psychosis, taking a broad view of involvement as described above in order to capture the barriers, problems and facilitating factors that operate in practice. In doing so, this may help to better define and implement families' involvement in psychiatric treatment in the future.

#### **METHODS**

The full protocol for this systematic review is reported in the Supplementary file 1.

## Identifying relevant studies

Computerised databases were searched for eligible studies: MEDLINE, EMBASE, PsycINFO, AMED (via Ovid), BNI and CINAHL (via HILO), Social Sciences Citations Index (via Web of Knowledge) and CDSR, DARE and CENTRAL (via the Cochrane Library). Word groups representing patient diagnosis, intervention and involvement terms and outcome descriptors were combined in several ways. Strategies were adapted for each database, using controlled vocabulary (MeSH, Emtree, Thesaurus of Psychological Index Terms) and free text (see Supplementary File 2). The search was last repeated on 01/06/2014.

Publication bias was minimised by including conference papers and book chapters, searching grey literature for dissertations and reports (ETHOS, SIGL) and corresponding with authors to identify further works. Both backward snowballing (from the reference lists of included studies and identified reviews) and forward snowballing (finding citations to the papers) was conducted.

#### **Inclusion procedure**

A study was eligible for inclusion if: 1) it was an original collection of data; 2) situated in primary or secondary mental health services; 3) the patient population included people being treated for psychotic disorders<sup>1</sup>; 4) the intervention involved tripartite communication between health professionals (any), families (unpaid carers) and adult patients, excluding those focused exclusively on professional–family communication, family-family communication or multiple-family groups; and 5) results described barriers, problems and/or facilitating factors in involving families in treatment. No study type was excluded, however only Latin-script languages were able to be translated.

'Barriers' were defined as factors that prevented an approach from taking place or limited the scope of it, 'problems' referred to issues that emerged when delivering an approach and 'facilitating factors' were considered to be any factors that aided implementation or delivery. 'Family involvement' was defined inclusively as any process allowing health professionals, families and patients to actively collaborate in treatment, such as in making joint treatment decisions. Studies not reporting clear information on how

<sup>&</sup>lt;sup>1</sup> Attempts were made where possible to focus on patients with psychosis, however many studies used opportunity sampling of mixed 'severe mental illness' groups, which were included in order to be as inclusive as possible.

families were involved in treatment were excluded. Studies into general experiences, opinions, satisfaction or needs were also excluded, unless they related to a clearly described specific involvement in treatment.

Two reviewers (EE and DG) screened all of the titles and collected relevant abstracts. These were screened and then excluded if they did not fit the selection criteria. Studies that seemed to include relevant data or information were retrieved and their full text versions analysed and examined for study eligibility. All final full text choices were confirmed and agreed by both reviewers.

## Method of Analysis

Data extraction and synthesis was guided by the *Economic and Social Research Council (ESRC)*'s Guidance on the Conduct of Narrative Synthesis in Systematic Reviews [55].

The included studies used both qualitative and quantitative methods, yet clearly had conceptual overlaps despite reporting results in different formats. Any available quantitative data were usually descriptive, reported in addition to qualitative findings and were largely used to explore existing themes or concepts. It was therefore considered appropriate to transform quantitative findings into qualitative form to systematically identify the main concepts across the studies using thematic analysis [55 , 56]. The use of this method is increasingly being advocated with studies involving data that are quantitative or from mixed methods [56-58] to address questions relating to intervention need, appropriateness and acceptability in systematic reviews [59].

#### Data extraction and synthesis

Theoretical Thematic Analysis [60] using inductive themes to identify the barriers, problems and facilitating factors of family involvement was used as a framework to explore further themes.

Two non-clinician researchers (EE and AD) independently extracted author interpretations and participant data from the included studies using a piloted data extraction sheet. They then separately allocated the findings to relevant sections of the framework (e.g. 'Barriers according to staff perspectives') and coded the data within each section. Identified categories (e.g. 'Unsupportive attitudes of managers') were aggregated into subthemes (e.g. 'Attitudes towards family work') and finally became grouped under overarching themes (e.g. 'Context: Addressing Organisational Culture'). These emerging themes were discussed throughout analysis along with a clinician-researcher (DG), and discrepancies were resolved through iterative discussions. Robustness of the synthesis was investigated and themes were checked for completeness. Two clinician-researchers (DG and SP) acted as third party assessors of the final data synthesis.

#### RESULTS

#### **Included studies**

Database searching produced 15615 titles to screen. After removing duplicates and irrelevant papers, a full text assessment of 119 documents was conducted. Twenty eight publications met our inclusion criteria and second stage searching including grey literature searching, personal correspondence and snowballing techniques led to the further identification and inclusion of 15 articles. This brought the final number of studies to 43. The PRISMA flowchart in Figure 1 depicts the identification and exclusion of articles. (Insert Figure 1 here).

#### **Overview of papers**

Forty-two papers were published between 1991-2013 and one in 1978. Just over half of the studies were based on UK findings, with the rest from Finland, the USA, Italy, Australia, Canada, Germany, India, Ireland, New Zealand, Spain, Greece and Portugal. Mainly, papers reported on experiences of implementing Family Intervention approaches (n=33). Typically these followed a similar structure and were broadly modelled on the Behavioural Family Therapy approach [61] (see Supplementary File 3 for full study characteristics). This included variations such as 'Psychosocial Intervention' and 'Family Psychoeducation'

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that fit the model of a Family Intervention. The remainder explored Open Dialogue approaches (n=6), Systemic Psychotherapy (n=3) and one purely Behavioural Therapy programme. The vast majority were cross-sectional studies and 13 were naturalistic evaluations, descriptions or case studies of a service. In all, 37 papers explored staff perspectives, eight papers featured patient perspectives and six featured 'family' perspectives. In total, the review included data of 588 professionals, 321 patients and 276 'family members' or 'families'.

#### In depth review: Synthesis across studies

Figure 2 summarises the final cross-study synthesis: the identified barriers/problems (in red) and facilitating factors (in green) and the themes in which they seemed to be operating. The themes closely relate to temporal sequencing in the process of delivering an intervention: the *context, engagement*, and then *delivery*. The figure provides a visual representation of the matches and gaps between barriers and facilitating factors related to involving families. This is for the most part conceptual, as barriers and their direct facilitating factors may not have been discussed in the same study. The themes and sub-themes are explored in greater detail in the synthesis below, which includes details of problems associated with delivering approaches that involve families as well as barriers and facilitating factors of this work.

(Insert Figure 2 here)

#### **Context:** Addressing the Organisational Culture

This theme reflects the majority of the findings, mostly from staff perspectives. Their experience of implementing family work could be characterised as working in relative isolation in a system where colleagues and managers did not value and prioritise family involvement or were openly hostile to it. With multi-disciplinary co-operation and working systems not in place, practical burdens associated with family

work were sometimes insurmountable. Mirroring this, factors that enabled family involvement to take place were related to top-down management support, prioritisation and changing the culture of family work.

#### Organisational Attitudes and Paradigms

This subtheme covered general attitudes, such as family involvement not being valued at organisational and team level but also highlighted possible entrenched reasons for this. For example, individualistic, biological paradigms made family work seem secondary or optional [62-64] and staff found it difficult to adopt a collaborative stance, relinquishing the role of didactic problem solver [63]. In some cases, it appeared that historical negative attitudes towards families had not shifted [62, 64]. Anti-family work attitudes described amongst colleagues ranged from resistance towards the approaches [63, 65-68] to well-intentioned but complicating beliefs regarding clinicians' duty towards the patient [64, 69, 70]. Facilitating factors related not only to specific strategies but to an overall shared culture and prioritisation of family work [64, 71, 72], shifting attitudes towards viewing the family as equal partners [71, 73] and thinking more systemically about problems [71, 74].

# Practical Needs Associated with Family Work

Overwhelmingly, staff reported on the practical burdens of family work: that it requires time, resources and funding and is difficult to integrate with other clinical casework [62, 64-70, 73, 75-87], particularly in areas with high demands and clinical crises [73, 82, 83]. Specific needs reported for family work included flexible hours [64, 65, 67, 70, 80, 82-84, 87-90] and the accommodation of family requirements such as childcare facilities [80] or home visits [82, 89, 91]. A lack of systems and structure for carrying out and recording family work was also reported as a barrier to implementation and problem during delivery [63, 87, 92]. This included a lack of co-ordination between inpatient and outpatient care [62]. These issues were compounded by reports of services and managers not making time allowances for family work, e.g. not providing time in lieu for out of hours work [64, 65, 77, 83, 84], or obstructing time use, e.g. by refusing the release of staff for training [63].

#### Management Culture

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Commonly, staff reported on the unsupportive attitudes of managers and colleagues as limiting the implementation of family involvement [63, 64, 66, 77-79, 87, 92, 93]. This ranged from a "*management culture of benign neglect rather than of active opposition*" [93] to overt challenges such as not respecting ring-fenced time for family work [87]. The strongest facilitator seemed to be that of strong leadership through senior management support and developing strategic solutions. This "sanctioned" family work, giving it core priority status within the service [64], and could facilitate specific powerful initiatives such as writing family work into business plans, policies and job descriptions of all staff [63, 79]. Further endorsement came from providing flexible hours, creating new staff roles and financial provision [63, 73, 79, 94]. The value emerged of having regular multi-disciplinary meetings to address team-specific needs [72, 78, 79, 88] and developing strategies that prioritised family work and made it a part of regular clinical practice [63, 72, 73, 79, 88, 94]. This included having routine assessment of all families, asking clinicians about families when reviewing caseloads and providing regular feedback of family data to teams and managers [63, 94].

#### Training Needs

Staff also reported on lacking access to adequate supervision and training [62, 63, 65, 66, 83, 86, 87, 92] as barriers to implementation. This may link with reports of staff lacking skills or confidence to do the work [62, 64, 85, 86, 92]. Some problems during delivery (such as managing family dynamics [64, 65, 70, 74, 78, 88, 95]) could also be related to staff skills and experience [71, 78, 81]. As expected, having a structured regime of supervision, encouraging attendance and ongoing support was described as helping staff to deliver work with families [63, 72, 78, 79, 88]. Staff also reported on the value of belief in the approach and having an identity in their role [71, 72, 79, 81, 86].

#### Team Attitudes, Commitment and Multi-disciplinary Co-operation

Difficulties arose when only a minority of team members had been trained in an intervention [82]. Staff reported that collaboration was often lacking [63, 65, 69, 73, 77, 80] and that involving families requires whole team commitment [76, 82]. 'Ownership' was sometimes an issue, with various staff groups

perceiving family work as within the domain of other roles, not theirs [69, 80]. Role and team-specific issues also emerged, such as psychiatrists, inpatient staff and home treatment teams being less involved [63, 66, 73, 81]. Collaboration in the form of multi-disciplinary co-working, peer-supervision and whole team approaches were all reported as aids to implementing family work [63, 66, 71-74, 78, 79, 82, 88].

Problems with finding 'appropriate' referrals were reported widely [65, 67, 68, 77, 78, 80, 82, 83, 93]. Whilst some patients do not have families, the pervasiveness of this response also called into question staff members' pre-existing ideas about what constitutes an 'appropriate' family for intervention. Staff reported the resistance of other professionals to make referrals [67, 88], family work services being "forgotten" and referrals being made as a "last resort", by which time the families themselves may have grown resistant [93]. Acting as a facilitator was the promotion of family work, both as a cascading effect through colleagues and across services [64, 79, 87].

## Engagement: Addressing Concerns through Openness, Encouragement and Building Alliances

The next theme related to the process of engagement, informed more broadly by both staff and family responses. A picture emerged of families sometimes being reluctant to engage, and of valid concerns. Yet the successful establishment of trusting relationships indicates these concerns may be surmountable in many cases.

#### Reservations about Involving Families

Similar issues around the nature of involving families emerged as a barrier to families becoming involved and as problems during treatment. Some concerns seemed linked to fears around power and control: bidirectional privacy concerns (keeping the extent of the illness from the family and keeping family issues from services) [70] and patients' fears of placing relatives in a position of power [70, 95] or of exposing their vulnerability [75]. Responses in all three participant groups addressed the need for an exclusive patient-

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professional relationship [69, 70, 76, 95]. Existing individual and family problems (such as patients' symptoms being directed at family members [62]) also precluded family involvement. Both families and staff expressed fears of making the current situation worse, such as by burdening the family and worsening the patient's symptoms [70, 80, 84, 86, 91]. Professionals described building trust and rapport, through open discussions with the family, acknowledging concerns and providing reassurance [71, 74, 88, 91].

#### Problems Engaging Families

These were often unspecified as scepticism, lack of motivation or refusal from the families, occurring prior to engagement or during treatment [65, 76, 78, 83, 84, 88, 93, 96]. As professional responses, these may reflect their attitudes towards families as unmotivated, but could also describe the failure of the team to mobilise the family in favour of treatment [96]. A factor described as a facilitator was having a critical period of engagement: intensive efforts at contact and involvement early on after contact with services [93, 96-99] and presenting the approach enthusiastically [71, 89] functioned to establish collaborative relationships between families and professionals as the modus operandi.

## Delivery: Active Collaboration, Professional Skills and Respect for Families as Individuals

The final theme related to factors that affected how staff members delivered family interventions and how families experienced them. As a whole, both family and staff responses highlight the importance of respectful, equal partnership, enhanced by professional skills and experience.

## Working Relationships between Families and Professionals

Collaboration between families and professionals on an equal footing appeared valued by both families and professionals. Lack of collaboration was cited as a problem during delivery, resulting in families feeling patronised or not understood [76]. Open Dialogue papers particularly emphasised the lack of success when actions were unilaterally decided, rather than emerging from a joint process [74, 99]. Factors helping to overcome this included being able to relinquish control, i.e. tolerate uncertainty in order to allow a joint

solution to emerge [78, 96, 98-100], approaching the family on an equal basis [71] and actively collaborating with families during meetings [66, 71, 89, 92, 96].

How families experienced an approach closely linked with their experience of the professional. Some families reported experiencing an approach as negative or critical, both through the model itself e.g. its characterisation of illness [101], or experiences of the professional, perhaps as criticising parenting [101, 102]. Yet, the interpersonal qualities of the professional and the establishment of a therapeutic alliance strongly emerged as facilitating factors: professionals being informed, genuine, warm, non-blaming [71, 89, 101] and demonstrating an awareness and understanding of the problems of the whole family [71, 79, 89, 90, 99].

A lack of continuity was cited as a problem [99], whilst a facilitator was having the same team involved from the beginning and staying with the family throughout the treatment process [96, 98, 99].

## Individualisation within the approach

Approaches were sometimes described as culturally insensitive [76, 88]: rigid, manualised approaches did not meet the general needs of particular groups whilst individual needs, such as illiteracy, were sometimes not catered to [64, 76, 97, 103]. Professionals and families valued having a clear structure whilst allowing for flexibility [71, 76, 88, 99]. Professionals' skills were also important, by way of communicating information in an easy-to-understand format, avoiding jargon [71, 88, 89, 99] and developing an individualised and contextualised approach [71, 76, 88, 93, 99].

## Working with Complex Needs

Professionals highlighted the complexities of working both with families and with patients with psychosis. The difficulties of managing patient symptoms and working in a meaningful way with their beliefs [73, 104] may be compounded by family dynamics [64, 65, 70, 74, 78, 88, 95, 104] and potentially relatives' own emotional and affective problems [104]. Staff members' qualities, skills and experience in the area

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were naturally described as facilitating factors [71, 76, 78, 79, 81, 83, 89, 90, 100]. Perhaps unsurprisingly, useful skills were described as working creatively to overcome barriers, hypothesising, reflecting and persevering [71, 79, 100].

#### DISCUSSION

### Main findings

Our results suggest that having 'top-down' support and training some staff members to carry out family work is necessary but not sufficient. In order to effectively implement family involvement in care, all members of a clinical team should be trained and regularly supervised and a 'whole team approach' should be used. Developing a clear structure for the intervention may be beneficial for the delivery of family involvement, provided that flexibility to accommodate individual needs is ensured. Concerns emerged regarding privacy, power relations, fear of negative outcomes and the need for an exclusive patientprofessional relationship. Exploring and acknowledging such concerns through open, yet non-judgemental communication could facilitate the establishment of a therapeutic alliance between staff, families and patients.

These findings may help to explain why family interventions – despite their overwhelming evidence base and their inclusion in practically all policies and guidelines – are so poorly implemented in routine practice. The requirements identified may be challenging given that family-oriented practice may need to be embraced by a whole organisation and included in work routines in order to be implemented.

#### **Strengths and limitations**

To our knowledge, this is the first systematic review that specifically focused on barriers, problems and facilitating factors for the implementation of family involvement in the treatment of patients with psychosis. This is of high importance given the current climate of government policies and psychiatric guidelines stipulating that families should be supported and actively involved in psychiatric treatment [6-11], and the

disappointments in achieving this in practice so far. The search strategy allowed for the capture of a large number of studies, different researchers independently extracted and reviewed the data and when necessary authors were contacted to clarify ambiguous information. The use of thematic analysis, described as having the "most potential for hypothesis generation" [108], allowed for understanding the larger picture, which is more than the sum of its findings. Whilst interpretative, this process has been carried out in accordance with RATS guidelines [61] and presented transparently. Though some themes were not highly recurrent -for example criticisms of manualisation emerged only in structured approaches such as Behavioural Family Therapy- in all, findings were complimentary, not contradictory. The fact that common themes emerged in spite of variations in approach, across 16 countries, speaks for the robustness of the findings as representing shared issues with family involvement.

However a number of limitations must be considered when interpreting the results of this study. Methodologically, conducting sub-group analysis, i.e. for different intervention models, was not considered viable due to the strong association between type of approach and methodology used e.g. Open Dialogue with case studies and Behavioural Family Therapy with the Family Intervention Schedule (FIS) questionnaire. Carrying out a sub-group analysis may have therefore had the risk of mischaracterising certain approaches due to variation in the richness of data. Whilst there are well-established methods for assessing the quality of intervention studies, this is not the case for studies of implementation processes, qualitative or mixed methods research [56] and the use of appraisal tools in qualitative research remains contentious [109, 110]. The decision not to use quality-based analysis was therefore also based on recognition of the important contribution and explanatory value that descriptive accounts offer. Despite efforts to find grey literature, the search strategy may still have been limited in its bias towards published research, yet the nature of this review topic means that service level audits and evaluations are likely to be of relevance. Conceptually, the dominance of staff and academic perspectives may have led to barriers within the organisation being explored most thoroughly, however does not lead to the conclusion that there are no inherent problems with involving families in clinical settings.

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## Comparison with available literature and implications for practice

Our findings reflect important key features for implementation of evidence based practices, already identified in previous research in implementation science, such as top-down input and leadership and the need for continuing consultation and training [105]. The presence of management and leadership decisions and strategies operating as barriers and facilitating factors throughout the organisational context –both directly and indirectly– aligns with findings that leadership at all levels (e.g. executive director, middle manager, clinical supervisor) is associated with innovation [106], implementation of evidence based practice (EBP) [107], and with improving the organisational context for EBP implementation [108]. The need for support from senior managers (and commissioners) and for a whole team approach is also reflected in the suggestions on how to implement family work in mental health services provided by professionals and carers with experience of participating in a Family Behavioural Therapy Programme, [109].

The fundamental role of the organisational context is emphasised in the literature with both culture (the normative beliefs and shared expectations of the organisation) and organisational climate (the psychological impact of the work environment on the professional) strongly moderating the uptake of evidence based practices [110]. The practice to be implemented must match the mission, values, tasks and duties of the organisation and individuals within that organisation [111]. The absence of a strong organisational culture favouring family work may be influenced by traditional paradigms based on the predominance of biological models of mental illness, which tend to minimise the focus on the individual's social context [50]. Also, the characterisations of families as dysfunctional and sometimes even as 'the cause of psychiatric illness,' despite being widely rejected [112], may have contributed to a loss of trust in services and strained relationships between professionals and families [113]. This may explain the importance and the effort required in building alliances, which emerged in our findings. Clinicians may uphold the patient-professional alliance by addressing concerns regarding privacy and by being mindful that patients do not perceive a loss of power due to having family involvement in their care.

## Future directions for research

So far the findings largely reflect what can go wrong rather than provide evidence of successful implementation. For example, sustainability has not been addressed in the review as this stage has hardly been reached. More research will be needed to see which organisational steps can actually change the culture in a service so that family involvement happens, not only in a research study or with particular patients, but with all families, every day, and over longer periods of time.

Future studies should attempt to better capture wider views, particularly in-depth understanding of patients' and families' views. This may also enable insight into the potentially varied experiences of minority groups. These views may be best obtained outside of group interviews, in which a power imbalance may be present. There would also be value in exploring the views of professionals who have not already demonstrated commitment to family work.

Despite a 'whole team approach' seeming to be the way forward for a widespread implementation of family work, there is a need to obtain insight into the organisational challenges that may be related to this and to develop clear practical guidelines for the reorganisation of clinical teams.

**Funding:** The research was partially funded by the National Institute for Health (NIHR) Research Collaboration for Leadership in Applied Health Research and Care (CLAHRC) North Thames at Barts Health NHS Trust.

Competing interests: The authors declare they have no competing interests.

Authors' contributions: DG, EE and SP contributed to the conception and design of the study. EE designed and conducted the search, DG and EE selected the studies. AD and EE extracted data and carried out the

thematic synthesis. EE wrote the manuscript, AD and DG reviewed and edited the manuscript and SP provided critical review of the manuscript. All authors contributed to and approved the final submitted version.

#### Acknowledgements: None

.s. No additional data available Data Sharing Statements: No additional data available

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## Figures & Table Legends

 Figure 1. PRISMA flow diagram for paper selection

Figure 2. Barriers, problems and facilitating factors related to family work. Summary of themes

Supplementary File 1. Protocol for Systematic Review

Supplementary File 2. Modified database search strategies

**Supplementary File 3.** Characteristics of included studies (n=43)

Studies excluded (n = 14556)

Duplicates (n = 6020)
Unrelated (n = 8536)

Studies excluded (n = 940)

• No empirical data (n = 444)

• Wrong patient group (n = 20)

Multiple publication (n = 5)

Studies excluded (n = 91)

• No empirical data (n = 16)

Multiple publication (n = 6)
Not possible to translate (n = 3)

 No details of involvement or not possible to isolate (n = 160)

No specific intervention/approach (n = 133)

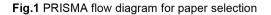
No evaluation of family involvement (n = 94)
Not single family involvement (n = 84)

• No evaluation of family involvement (n = 22)

• No details of involvement or not possible to isolate (n = 12)

No specific intervention/approach (n = 8)
Not possible to locate (n = 6)

Not single family involvement (n = 18)



Potentially relevant studies

identified for retrieval and titles screened (n = 15615)

Abstracts screened for more detailed evaluation

(n = 1059)

Full texts screened for more detailed evaluation (n = 119)

Papers included in review (n = 43)

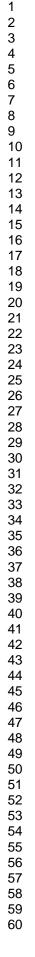
PRISMA flow diagram for paper selection

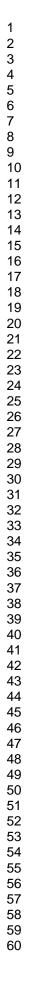
150x150mm (300 x 300 DPI)

Additional papers included

through grey literature searching, snowballing and

screening references (n = 15)





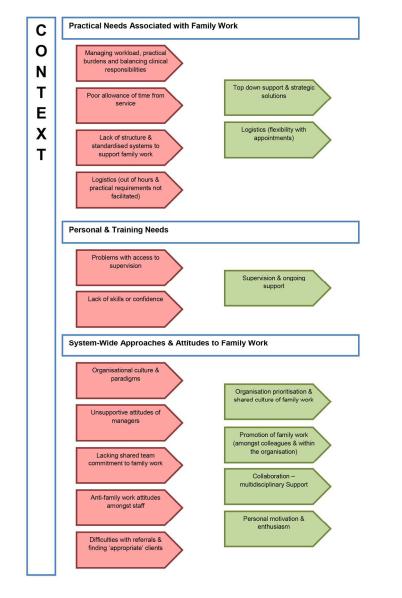


Figure 2. Barriers, problems and facilitating factors related to family work. Summary of themes (Page 1 of 2).

Barriers, problems and facilitating factors related to family work. Summary of themes (Page 1). 172x233mm (300 x 300 DPI)

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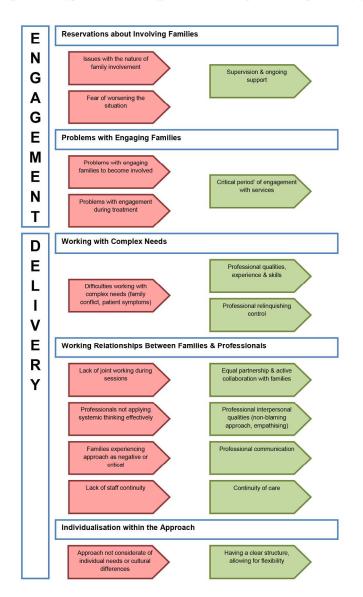


Figure 2. Barriers, problems and facilitating factors related to family work. Summary of themes (Page 2 of 2).

Barriers, problems and facilitating factors related to family work. Summary of themes (Page 2). 165x233mm (300 x 300 DPI)

## Supplementary file: Protocol for a Systematic Review

# Implementing family involvement in treatment of psychosis: A Systematic Review of facilitating and hindering factors

Domenico Giacco, Erica Eassom & Stefan Priebe

## Background and rationale for a review

Due to the move of psychiatric care from hospitals to community, nowadays informal caregivers (i.e. family or friends) have taken some functions performed in the past by psychiatric institutions. Consequently, "informal care" plays a significant role in development and evaluation of health programs and policies (Clark & Drake, 1994; Simpson, 2008; Caqueo-Urizar et al., 2009).

An estimated 40-50% of almost six million carers in the United Kingdom provide care for another family member or friend with a mental health problem (Office for National Statistics 2003). In particular, it has been estimated that carers of people with schizophrenia save the public purse £1.24 billion per year (Schizophrenia Commission Report, 2012).

Many psychiatric policies and guidelines stipulate that families should be supported and actively involved in psychiatric treatment (Department of Health, 2006; National Institute of Mental Health in England, 2004; NICE, 2011). The Schizophrenia Commission Report (2012) states that "Services need to make a fundamental reappraisal of how they treat families and put them at the centre of their thinking and practice". This document also emphasizes that "carers are seen as resource, experts, partners in care". Recent evidence from large scale European and UK studies has documented that relatives wish to be more involved in the care of their ill relatives, also during acute phases of their illness (Jankovic et al., 2011; Giacco et al., 2012).

Family involvement in treatment is often seen as intrinsically worthwhile; however some positive consequences in terms of patients' outcomes and patients and families' satisfaction with treatments have also been hypothesized (Simpson and House, 2003).

However, a number of barriers to family involvement in treatment and problems in its implementation in routine practice have been also identified (Simpson and House, 2003) such as: danger of increasing burden related to caregiving, role strain, lack of experience and/or interest. Also, specific problems may arise in different phases of the illness (e.g. when the patient is acutely ill and requires involuntary treatment).

This study will systematically review the available studies exploring family involvement in routine psychiatric treatment. Assessing barriers, problems and facilitating factors related to family involvement will help better define and implement family involvement in clinical practice.

## **Research questions**

The review will aim at answering the following research questions:

1. What are the barriers that may prevent family involvement?

- 2. What are the problems that may arise during implementation of family involvement?
  - 3. What are the facilitating factors for family involvement?

The different perspectives of patients, their family members and staff will be assessed.

## Selection criteria

## 1) Study type

Conducted in general public mental health services Any type of study design (qualitative, quantitative and mixed) Published in Latin script

2) Participants

## Patients

People with psychotic disorders (F20-29 and F31 according to ICD-10) Age 18-65/ any gender/nationality

## Family/Carers

Family and informal (i.e. non-professional) carers: relatives, friends, others Any age /gender/nationality

Either main carer (i.e. spending most time with the patient) or other carers

## <u>Staff</u>

Any mental health professional (psychiatrists, psychologists, nurses, social workers, care coordinators, occupational therapists)

## 3) Family involvement

Explicit description of family involvement (i.e. information, support, involvement in decision making, preparation of crisis plans, etc.)

Assessment of carer's involvement through assessment of barriers or problems or facilitating factors or feasibility

## Exclusion criteria

- 1) Studies assessing family involvement in planning of services will be excluded
- 2) Studies not reporting clear information on how family involvement was implemented (services' catchment area, description of activities, i.e. information, support, involvement in decision making, preparation of crisis plans, etc.)
- 3) Studies into general experience, opinions, satisfaction or needs, unless related to a clearly described carer involvement in treatment
- 4) Studies reporting on therapy for the family or group psychoeducation, i.e. the carer involvement will have to be in the context of the treatment of an individual patient

## Methods

In order to gather relevant literature, electronic searches of electronic databases will take place. In addition, the articles included as references in the review papers found will be hand searched too.

Databases to be searched include:

- BNI
- CINAL
- EMBASE
- MEDLINE
- PsychINFO
- CENTRAL
- AMED
- Social Sciences Citations in Web of Knowledge

Hand searching of review articles on the topic and of included studies Grey literature will also be searched, including:

- Dissertations/PhDs
- Contacting authors in the field
- Forward and backward snowballing related to citations

The abstracts of the papers identified will be examined to determine papers potentially relevant to the review. Based on this initial screening, selected full-text articles will be obtained for a second-stage screening. Studies will be included and submitted for data extraction if they specifically address family involvement in the treatment of patients with psychosis and if the tasks in which the family is involved are specifically described.

## **Extraction process**

Search terms will be a mixture of family/carers' involvement descriptors, psychosis descriptors and outcomes.

Family/Carers' involvement descriptors	Psychosis descriptors	Outcome descriptors	
Carers	Psychosis	Clinical outcomes	Experiences
Caregivers	Schizophrenia	Symptoms	Benefits
Relatives	Psychotic disorders	Hospitalizations	Rewards
Friends	Schizoaffective disorder	Quality of life	Failures
Family support	Schizophreniform disorder	Adherence	Challenges
Family burden	Severe mental illness	Satisfaction with treatment	Difficulties
Involvement	Acute phase	Care	Barriers
Social support	Crisis	Satisfaction	Stress
Practical support		Experiences	Empowerment
Inpatient treatment		Service provision	
Outpatient treatment		Psychiatric services	
Involuntary hospitalization		Opinions	
Psychoeducation		Attitude	

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Supplementary File. Modified database search strategies

## EMBASE/MEDLINE/PSYCHINFO/AMED via Ovid

- 1. exp schizophrenia/ or exp psychosis/
- 2. 1 use emez
- 3. exp schizophrenia/ or exp psychotic disorders/
- 4. 3 use mesz
- 5. exp psychosis/ or schizoaffective disorder/
- 6. 5 use psyh
- 7. exp bipolar disorder/
- 8. (psychos#s or psychotic or schizo\$ or bipolar disorder).ti,ab.
- 9. ((chronic\$ or serious or severe\$) adj (mental\$ or psychological\$ or psychiatric) adj (disorder\$ or ill\$ or health or problem\$)).mp.
- 10. Or/2,4,6-9
- 11. ((famil\* adj2 therapy) or family psychiatry or family psychotherapy or family counselling or family work or family treatment or family intervention or family management or family approach\$).mp. [mp=ti, ab, sh, hw, tn, ot, dm, mf, dv, kw, nm, kf, ps, rs, ui, tc, id, tm]
- 12. ((carer or caregiver\$ or relative\$ or friend\$ or family or families) adj2 (partner\$ or work\$ with or support\$)).mp.
- 13. ((carer\$ or caregiver\$ or relative\$ or friend\$ or family or families) adj5 (program\$ or psychoeducation\$ or integrate\$ or train\$ or inform\$ or service\$ or intervention\$ or initiative\$ or psychosocial)).mp
- 14. ((carer\$ or caregiver\$ or relative\$ or friend\$ or family or families) adj (involv\$ or inclu\$)).mp.
- 15. or/11-14
- 16. (benefit\$ or advantage\$ or success\$ or fail\$ or problem\$ or disadvantage\$ or challenge\$ or barrier\$ or difficult\$ or issue\$ or experience\$ or satisf\$ or evaluat\$ or obstacle\$).ti,ab.
- 17. 10 and 15 and 16

## **BNI/CINAHL via HILO**

- (psychos?s OR psychotic OR schizoaff\* OR schizophr\* OR "bipolar disorder" OR "manic depression" OR "severe\* mental\* ill\*" OR "severe\* mental\* disorder\*" OR "serious\* mental\* ill\*" OR "serious\* mental\* disorder\*" OR "severe mental health" OR "serious mental health").ti,ab
- ("family therapy" OR "family psychiatry" OR "family psychotherapy" OR "family counselling" OR "family work" OR "family treatment" OR "family intervention" OR "family management" OR "family approach\*").ti,ab,mw,su
- 3. ((carer\* OR caregiver\* OR relative\* OR friend\* OR family OR families) AND (partner\* OR "work\* with" OR support\* OR program\* OR psychoeducation\* OR integrate\* OR train\* OR inform\* OR service\* OR intervention\* OR initiative\* OR psychosocial OR involv\* OR inclu\*)).ti,ab

4. 2 OR 3

- (benefit\* OR advantage\* OR success\* OR fail\* OR problem\* OR disadvantage\* OR challenge\*
   OR barrier\* OR difficult\* OR issue\* OR experience\* OR satisf\* OR evaluat\* OR obstacle\*).ti,ab
- 6. 1 AND 4 AND 5

## Social Sciences Citations Index via Web of Knowledge

1. TS=(psychosis OR psychoses OR psychotic OR schizoaff\* OR schizophr\* OR "bipolar disorder" OR "manic depression" OR "severe\* mental\* ill\*" OR "severe\* mental\* disorder\*" OR "serious\* mental\* ill\*" OR "serious\* mental\* disorder\*" OR "severe mental health" OR "serious mental health")

2. TS=("family therapy" OR "family psychiatry" OR "family psychotherapy" OR "family counselling" OR "family work" OR "family treatment" OR "family intervention" OR "family management" OR "family approach\*")

3. TS=((carer\* OR caregiver\* OR relative\* OR friend\* OR family OR families) AND (partner\* OR "work\* with" OR support\* OR program\* OR psychoeducation\* OR integrate\* OR train\* OR inform\* OR service\* OR intervention\* OR initiative\* OR psychosocial OR involv\* OR inclu\*))

## 4. #2 OR #3

5. TS=(benefit\* OR advantage\* OR success\* OR fail\* OR problem\* OR disadvantage\* OR challenge\* OR barrier\* OR difficult\* OR issue\* OR experience\* OR satisf\* OR evaluat\* OR obstacle\*)

6. #1 AND #4 AND #5

Refined by: [excluding] Research Areas NEUROSCIENCES NEUROLOGY OR PHARMACOLOGY PHARMACY OR GENERAL INTERNAL MEDICINE OR PEDIATRICS OR GERIATRICS

## CDSR/DARE/CENTRAL via the Cochrane Library

- 1. . MeSH descriptor: [Schizophrenia] explode all trees
- 2. MeSH descriptor: [Psychotic Disorders] explode all trees
- 3. MeSH descriptor: [Bipolar Disorder] explode all trees
- 4. MeSH descriptor: [Affective Disorders, Psychotic] this term only
- 5. (chronic or serious or severe) next (mental or psychological or psychiatric) next (health or disorder or ill or problem) (Word variations have been searched)
- 6. Psychosis (Word variations have been searched)
- 7. {or #1-#6}

## **BMJ Open**

- 8. (family next therapy) or (family next psychiatry) or (family next psychotherapy) or (family next counselling) or "family work" or (family next treatment) or (family next intervention) or "family management" or "family approach\*" (Word variations have been searched)
- 9. (carer OR caregiver OR relative OR friend OR family) NEAR (partner OR "work\* with" OR support OR program OR psychoeducation OR integrate OR train OR inform OR service OR intervention OR initiative OR psychosocial OR involve OR include) (Word variations have been searched
- 10. benefit or advantage or success or fail or problem or disadvantage or challenge or barrier or difficult or issue or experience or satisf\* or evaluate or obstacle)
- 11. #8 or #9
- 12. #7 and #10 and #11 in Cochrane Reviews (Reviews and Protocols), Other Reviews and Trials

<text>

Supplementary File 3: Table of Characteristics of included studies (n=43)

Country of origin, language, year of publication	Published Form	Principal objective of the study	Operationalisation of family involvement	Type of psychiatric service	Study design eliciting barriers and facilitating factors	Participants data used in review	Methods releva to review
UK (England), English, 2013 [75]	Journal Article	To explore the meaning and significance of FI for the individual who experiences psychosis, and its significance for recovery.	Family Intervention. 'Integrated Family Intervention'; 'S.T.E.P. Service' individual and family CBT with systemic perspective: psychoeducation, needs assessment for further FI: problem solving, behavioural goal setting, medication management, relapse management, skills training.	Specialised (Family Intervention Service), Outpatient	Cross- sectional, Qualitative	7 individuals with experience of psychosis and the FI service: diagnoses included schizophrenia, bipolar disorder, and severe depression.	Semi-structured interviews
New Zealand, English, 1997 [76]	Journal Article	To measure the implementation of the 'Integrated Mental Health Care' approach 1 year after training and explore barriers and benefits; to provide information about participants' perceptions and experiences.	Family Intervention. 'Integrated Mental Health Care' community-based approach influenced by the BFT model of Falloon and colleagues (F- BFT): needs assessment, psychoeducation, skills training.	General, Outpatient	Cross- sectional, Mixed Methods	11 CPNs, 7 community workers, 5 OTs, 3 SWs, 2 managers, 1 psychiatrist, 1 psychiatric registrar, 1 activity centre coordinator, 1 liaison officer, 1 CP, 1 therapist.	a) Questionnair (rating scale) b) Semi-structu interviews
UK (England), English, 2000 [77]	Book Chapter	To investigate how FI had been integrated into former 'Thorn Course' trainees' routine work, examine the nature of any difficulties and determine if it is possible to predict which trainees would be more able to implement FI skills acquired during training.	Family Intervention. 'Psychosocial Family Interventions for psychosis': formulation driven, cognitive behavioural family approach: needs assessment, education, skills training.	General, Inpatient & Outpatient	Cross- sectional, Mixed Methods	16 community-based MHNs, 2 ward-based MHNs, 2 managers, 1 lecturer.	Questionnaire (rating scale & ended response
UK (England), English, 2003 [78]	Journal Article	To examine the effectiveness of the 'FIRST' FI training programme and compare experiences of staff in Somerset with staff in previous studies.	<b>Family Intervention.</b> 'Psychosocial Family Interventions for psychosis' based on the 'S.T.E.P. Service' model: individual and family CBT with systemic perspective: needs assessment, education, skills training.	General, Inpatient & Outpatient	Cross- sectional, Mixed Methods	8 CPNs, 5 MHNs, 2 SWs, 1 psychiatrist, 1 CP, 1 art therapist.	a) Questionnair (rating scale & c ended response b) Focus group
India, English, 2012 [88]	Journal Article	To report on the researching, planning and delivery of a pilot of a community- based intervention for people with schizophrenia and their carers, delivered by lay health workers.	<b>Family Intervention.</b> Community-based intervention for people with schizophrenia and their families: weekly home based sessions, needs assessment, psycho-education, adherence management, rehabilitation, health promotion.	General, Outpatient	Case Study	N/A	Descriptive acc
UK (England), English,	Journal article	To examine the experiences of trainers on the 'Meriden - West Midlands Family Programme' programme, including	<b>Family Intervention.</b> 'Meriden Family Work Programme' based on F-BFT. 10 to 14 sessions: psychoeducation, relapse planning,	General, Not Reported	Cross- sectional, Qualitative	42 Behavioural Family Therapy trainers.	Structured writte and phone questionnaires

1 2								
3 4	2001 [79]		motivations, frustrations, benefits and support from being involved in Meriden.	skills training.				(open-ended responses)
5 6 7 8	UK (England), English, 1997 [65]	Journal Article	To establish the prevailing issues and working practices of qualified Mental Health Nurses carrying out FI.	<b>Family Intervention.</b> 'Schizophrenia Family Work', based on F-BFT principles: psychoeducation, problem solving, skills training.	General, Inpatient & Outpatient	Cross- sectional, Mixed Methods	36 CPNs, 2 ward-based MHNs.	Questionnaire (rating & open- ended response)
9 10 11 12	United States, English, 2007 [62]	Journal Article	To discuss barriers to implementing FI in the treatment of psychotic-spectrum illnesses, in both inpatient and outpatient settings.	<b>Family Intervention.</b> 'Family focused evidence based treatment': psychoeducation, problem solving, skills training.	General, Inpatient & Outpatient	Case Study	N/A	a) Descriptive account b) Case study
13 14 15 16 17 18	UK (England), English, 1991 [66]	Journal Article	To describe the effect on the role and function of the Community Psychiatric Nurse after training to deliver psychosocial intervention to families caring for a relative with schizophrenia living at home.	<b>Family Intervention.</b> 'Psychosocial Intervention', based on F- BFT: needs assessment, psychoeducation, skills training, problem-solving, medication compliance, crisis planning, cognitive behavioural management strategies.	General, Outpatient	Cross- sectional, Mixed Methods	18 CPNs.	Questionnaire (rating & open- ended response)
19 20 21 22 23 24	UK (Wales), English, 1997 [101]	Journal Article	To investigate what carers found helpful and unhelpful about the community-based FI programme.	<b>Family Intervention.</b> Based on the 'S.T.E.P. Service' model of individual and family CBT with systemic perspective: psychoeducation; needs assessment for further FI: problem solving, behavioural goal setting, medication management, relapse management, skills training.	General, Outpatient	Cross- sectional, Qualitative	20 relatives of people with a diagnosis of schizophrenia or schizoaffective disorder.	Semi-structured interviews
25 26 27 28 29	Ireland, English, 2014 [68]	Journal Article	To investigate participants' use of PSI in clinical practice following postgraduate training.	<b>Family Intervention.</b> 'Psychosocial Intervention', based on F-BFT: needs assessment, psychoeducation, skills training, problem-solving, medication compliance, crisis planning, cognitive behavioural management strategies.	General, Inpatient & Outpatient	Cross- sectional, Qualitative	8 MHNs.	Questionnaire (open-ended response)
30 31 32 33 34	UK (England), English, 2004 [89]	Journal Article	To describe the lived experiences of families who had received the family intervention of BFT.	<b>Family Intervention.</b> 'Meriden Family Work Programme' based on F-BFT: psychoeducation, skills training, relapse management, problem solving.	General, Outpatient	Cross- sectional, Qualitative	9 service users with a diagnosis of severe mental illness (schizophrenia, bipolar disorder, severe depression), 18 family members.	Semi-structured family interviews
35 36 37 38 39 40	United States, English, 2010 [80]	Journal Article	To study the implementation of an FI in order to perform a process analysis of implementation and examine utilisation of the intervention.	<b>Family Intervention.</b> 'Psychoeducation & EQUIP (Enhancing Quality of Care in Psychosis)': family outreach, needs assessment and care coordination, medication management, and optional further family intervention.	Specialised (Veterans Affairs), Outpatient	Cross- sectional, Mixed methods	173 patients with a diagnosis of schizophrenia or schizoaffective disorder; 18 clinicians (psychiatrists and psychiatry residents).	<ul> <li>a) Questionnaire</li> <li>(ratings and open- ended responses)</li> <li>b) Semi-structured</li> <li>interviews.</li> </ul>
40 41 42 43 44	Spain, Spanish,	Journal Article	To describe the implementation process of a family psychoeducation programme	<b>Family Intervention.</b> Based on F-BFT: psychoeducation, problem solving, skills	General, Outpatient	Case Study	N/A	Descriptive account
45 46 47 48 49			For peer review o	nly - http://bmjopen.bmj.com/site/abou	ut/guideline	s.xhtml		

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3 4	2011 [81]		in nine mental health services in Spain.	training, relapse management.				
5 6 7 8 9	Italy, Italian, 2011 [67]	Journal Article	To identify benefits and barriers in implementing a family psychoeducation programme, according to professionals' perspectives and participation of families to the programme.	<b>Family Intervention.</b> Based on F-BFT: psychoeducation, problem solving, skills training, relapse management.	General, Outpatient	Cross- sectional, Mixed methods	10 psychiatrists, 5 CPs, 6 MHNs and 1 rehabilitation therapist.	a) Descriptive reports of attrition b) Questionnaire (ratings and open- ended responses).
10 11 12 13	UK (England), English, 2009 [63]	Book Chapter	To provide an organisational case analysis of implementing a new family service programme in one UK Trust.	<b>Family Intervention.</b> 'Meriden Family Work Programme' based on F-BFT: psychoeducation, skills training, relapse management, problem solving.	General, Inpatient & Outpatient	Case Study	N/A	Descriptive account
14 15 16 17	UK (England), English, 2002 [64]	Book Chapter	To describe a strategic approach to the implementation of evidence-based approaches to family interventions in the UK West Midlands area.	<b>Family Intervention.</b> Based on the 'Meriden Family Work Programme' used by Fadden and colleagues: psychoeducation, skills training, relapse management, problem solving.	General, Inpatient & Outpatient	Case Study	N/A	Descriptive account
18 19 20 21 22 23	UK (England), English, 1997 [82]	Journal Article	To ascertain the extent to which therapists trained in BFT have used the skills in their day-to-day work, to examine what difficulties they had encountered and to define outcomes and factors related to success.	Family Intervention. Based on Fadden's 'Meriden Family Work Programme': psychoeducation, skills training, relapse management, problem solving.	General, Inpatient & Outpatient	Cross- sectional, Mixed methods	35 CPNs, 20 MHNs, 9 psychiatrists, 8 OTs, 7 SWs, 7 rehabilitation officers.	a) Questionnaire (Rating and open- ended responses) b) Between group comparison of ratings
23 24 25 26 27 28 29 30	UK (Scotland), English, 2004 [97]	Journal Article	To compare and contrast different elements of PSI courses and how they may impede/facilitate implementation, understand organisational catalysts/barriers and chart the relationship between organisation, educational and care arrangements on the use of PSI.	Family Intervention. 'Psychosocial Intervention', developed from F-BFT: assessment of relatives, psychoeducation, skills training, problem-solving, crisis management, cognitive-behavioural management strategies.	General, Outpatient	Cross- sectional, Qualitative	3 service managers, 7 lecturers, 16 mental health workers.	Semi-structured interviews
31 32 33 34	Canada, English, 2006 [69]	Journal Article	To compare family nursing interventions of nurses before and after an educational programme based on the Calgary Family Assessment Model and Calgary Family Intervention Model and to explore perceptions of the programme.	<b>Systemic Psychotherapy.</b> 'Family systems nursing approach': Targeting interactions between members of the family and between the family and practitioner.	General, Inpatient	Cross- sectional, Qualitative	7 MHNs.	a) Content analysis of logbooks b) Semi-structured interviews
35 36 37 38 39	Australia, English, 2008 [94]	Conference Paper	To evaluate service implementation of the 'Building Family Skills Together Programme'.	<b>Family Intervention.</b> Based on Fadden's 'Meriden Family Work Programme': psychoeducation, skills training, relapse management, problem solving. 'Family Sensitive Practice' and a Family Practice Consultant embedded in each service.	General, Outpatient	Case Study	N/A	Descriptive account
40 41 42 43 44	Germany, English, 2013 [73]	Journal Article	To assess the feasibility of continuous implementation of SYMPA (systems therapy methods in acute psychiatry)	Systemic Psychotherapy. A systemic resource-oriented and solution-oriented psychotherapeutic treatment.	General, Inpatient	Cross- sectional, Qualitative	Staff trained in the SYMPA method: survey 51, interviews 56 (overlap in	a) Questionnaire (rating and open- ended responses)
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3 4			related methods.				participants).	b) Semi-structured interviews
5 6 7 8 9	UK (England), English, 1978 [91]	Journal Article	To identify problems associated with implementing a behavioural intervention.	<b>Behavioural Therapy.</b> 'Behavioural Modification': Operant conditioning with the assistance of family members to reinforce "good" behaviours and discourage unhelpful ones, needs assessment, information and individualised practical support and advice for families.	General, Outpatient	Case Study	N/A	Descriptive account
10 11 12 13 14	UK (Wales), English, 1996 [93]	Journal Article	To present an account of implementing FI within a routine clinical service rather than as part of a specially funded research project.	<b>Family Intervention.</b> Based on the 'S.T.E.P. Service' model: psychoeducation; needs assessment for further FI: problem solving, behavioural goal setting, medication management, relapse management, skills training.	Specialised (Family Intervention Service), Outpatient	Case Study & Audit report, Mixed methods	N/A	a) Descriptive account b) Audit results
15 16 17 18 19	UK (England), English, 2006 [71]	Journal Article	To establish what therapists and families believe to be helpful (or otherwise) in the engagement of families in Behavioural Family Therapy.	Family Intervention. F-BFT based model: needs assessment, psychoeducation, individual problem-solving approach, skills training.	Generic, Inpatient & Outpatient	Cross- sectional, Qualitative	2 MHNs, 1 OT, 1 CP, 1 physiotherapist, 1 SW, 1 nurse manager; 7 relatives: 3 mothers, 2 fathers, 1 step-father, 1 daughter.	Semi-structured interviews
20 21 22 23 24	Australia, English, 1993 [83]	Journal Article	To identify staff members' difficulties in applying the FI and to predict the systematic use of the intervention with families.	Family Intervention. 'Living with Schizophrenia' programme: needs assessment, interactive psychoeducation, relapse management, goal-setting, problem solving, cognitive-behavioural self-management.	General Outpatient	Cross- sectional, Quantitative	29 MHNs, 8 CPs, 2 OTs, 3 SWs, 2 psychiatric registrars and 1 psychiatrist.	a) Questionnaire (ratings and examination of intervention knowledge) b) Regression analysis
25 26 27 28 29	UK (England), English, 2010 [72]	Journal Article	To evaluate a cross-educational practice meeting in assisting 'Thorn Course' graduates to implement PSI into clinical practice.	Family Intervention. 'Psychosocial Intervention' Thorn model, developed from F- BFT: assessment of relatives, psychoeducation, skills training, problem- solving, crisis management, cognitive behavioural management strategies.	General, Not Reported	Cross- sectional, Qualitative	8 Thorn graduates, 4 line managers, 2 Thorn lecturer practitioners, 1 operational services director.	Semi-structured interviews
30 31 32 33 34 35	International (Greece, Germany, Italy, Portugal, Spain, UK), English, 2005 [84]	Journal Article	To investigate the implementation and effectiveness of a standard psychoeducational family intervention in six European countries, exploring feasibility, difficulties, benefits and impact.	<b>Family Intervention.</b> Based on F-BFT: psychoeducation, problem solving, skills training, relapse management.	General, Inpatient & Outpatient	Cross- sectional, Mixed methods	15 psychiatrists, 14 MHNs, 7 CPs, 7 SWs, 1 OT, 4 other.	Questionnaire (rating and open- ended responses)
36 37 38 39	Italy, English, 2006 [85]	Journal Article	To investigate feasibility of providing psychoeducational interventions for persons with schizophrenia and their families.	<b>Family Intervention.</b> Based on F-BFT: psychoeducation, problem solving, skills training, relapse management.	General, Outpatient	Cross- sectional, Mixed methods	15 psychiatrists, 11 MHNs, 5 CPs, 4 rehabilitation therapists, 3 SWs.	Questionnaire (rating and open- ended responses)
40 41 42 43 44	UK (England), English,	Journal Article	To describe the use of the theory-based implementation interview (TBII) to understand the difficulties in implementing	<b>Family Intervention.</b> Psycho-education, problem solving, crisis planning, and individualised patient interventions.	General, Outpatient	Cross- sectional, Qualitative	6 SWs, 5 MHNs, 4 team managers, 3 CPs, 2 psychiatrists.	Semi-structured interviews
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3 4	2007 [86]		the family intervention recommendation within NICE's Schizophrenia guideline in					
5 6 7 8 9	UK (England), English, 2013 [92]	Journal Article	three UK NHS Mental Health Trusts. To investigate trainee participant understanding of the use of family interventions in their clinical area, identify themes related to implementation into practice following completion of the module.	<b>Family Intervention.</b> Integration of F-BFT and family CBT models: needs assessment, use of behavioural interventions related to stress management and problem solving, relapse management.	General, Not Reported	Cross- sectional, Mixed Methods	5 trainees enrolled in the family intervention module.	Semi-structured interviews
10 11 12 13	UK (England), English, 2007 [87]	Journal Article	To highlight issues encountered in service development and discuss development of the pilot project with a focus on why people who are trained in FI do not utilise the skills.	<b>Family Intervention.</b> Integration of F-BFT and family CBT models: needs assessment, use of behavioural interventions related to stress management and problem solving, relapse management.	General, Inpatient & Outpatient	Case Study & Cross- sectional, Qualitative	N/A	a) Descriptive account b) Focus groups
14 15 16 17	UK (Northern Ireland), English, 2008 [100]	Journal Article	To explore the roles and perspectives of mental health nurse practitioners towards clients with enduring mental illness and their carers following completion of PSI training.	<b>Family Intervention.</b> 'Psychosocial Intervention', developed from F-BFT: needs assessment, psychoeducation, skills training, problem-solving, relapse management, cognitive behavioural management strategies.	General, Inpatient & Outpatient	Cross- sectional, Qualitative	8 MHNs.	Focus groups
18 19 20 21	UK (England), English, 2011 [70]	Journal Article	To examine the views of service users, relatives and care-coordinators of the value and barriers of involving family members in relapse prevention.	<b>Family Intervention.</b> 'Relapse Prevention Programme': six 1h manualised sessions; psychoeducation, relapse management, skills training, crisis intervention planning.	General, Outpatient	Cross- sectional, Qualitative	18 CPNs, 2 OTs, 1 SW; 21 individuals diagnosed with Bipolar Disorder; 10 relatives: 6 spouses, 3 parents, 1 sibling	Semi-structured interviews
22 23 24 25 26 27	Finland, English, 2009 [95]	Journal Article	To determine how the participation of relatives in treatment was experienced by the relatives themselves, by the patients and by staff members and what the consequences of such participation were.	<b>Open Dialogue.</b> Rapid early involvement within 24 hours, as often as needed; meetings with any members of the patient's social network; collaborative participation of the patient and social network in every phase of decision making and treatment.	General, Outpatient	Cross- sectional, Qualitative	8 psychiatrists, 5 CPs, 9 MHNs; 10 individuals diagnosed with Schizophrenia; 14 relatives: 4 mothers, 1 father, 3 sisters, 1 brother, 3 spouses, 2 ex-spouses, 1 cousin.	Semi-structured family interviews
28 29 30 31 32	Finland, English, 2004 [103]	Journal Article	To elucidate the experiences and importance of co-operation [in treatment] for the patients.	<b>Open Dialogue.</b> Rapid early involvement; social network meetings; collaborative decision making and treatment.	General, Outpatient	Cross- sectional, Qualitative	22 individuals receiving treatment: 9 Psychosis Spectrum Disorder; 6 Depressive or Anxiety Disorder; 7 Other mental disorder.	Semi-structured interviews
33 34 35	Finland, English, 2006 [98]	Journal Article	To illustrate Open Dialogue process and treatment principles, with illustration from case studies, 5 years on from introduction.	<b>Open Dialogue.</b> Rapid early involvement; social network meetings; collaborative decision making and treatment.	General, Inpatient & Outpatient	Case Study	N/A	a) Descriptive account b) Case series
36 37 38	Finland, English, 2001 [99]	Journal Article	To illustrate Open Dialogue process and treatment principles, with illustration from a case study.	<b>Open Dialogue.</b> Rapid early involvement; social network meetings; collaborative decision making and treatment.	General, Inpatient & Outpatient	Case Study	N/A	a) Descriptive account b) Case study
39 40	Finland, English, 2001 [96]	Journal Article	To illustrate Open Dialogue process and treatment principles, using examples of poor and good outcome case studies.	<b>Open Dialogue.</b> Rapid early involvement; social network meetings; collaborative decision making and treatment.	General, Inpatient & Outpatient	Case Study	N/A	a) Descriptive account b) Case series
41 42 43	Finland, English,	Journal Article	To clarify the co-evolving process between the family and hospital and	<b>Open Dialogue.</b> Rapid early involvement; social network meetings; collaborative decision	General, Inpatient &	Case Study	N/A	a) Descriptive account
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3 4	1994 [74]		report some results using the Open Dialogue approach.	making and treatment.	Outpatient			b) Case study
5 6 7 8	UK (England), English, 2003 [90]	Journal Article	To evaluate the Family Support Service in terms of satisfaction, clinical outcome, investigating aspects families found helpful/unhelpful and other factors possibly linked with satisfaction/outcome.	Family Intervention. 'Psychosocial Family Interventions for psychosis' following 'FIRST course' training: individual and family CBT with systemic perspective: needs assessment, education, skills training.	Specialised (Family Support Service), Outpatient	Cross- Sectional, Qualitative	13 family interviews (23 individuals in total). Patients had 'psychotic symptoms'.	Group interview
9 10 11 12 13 14	United States, English, 2000 [104]	Journal Article	To examine the relationship between independent observers' and therapists' ratings of difficulty in implementing family treatment for patients with bipolar disorder and pre-treatment measures of relatives' emotional attitudes (EE), affective behaviours during family interactions, and patients' residual symptoms.	<b>Family Intervention.</b> 'Family Psychoeducation' adapted from F-BFT: psychoeducation, communication training, problem-solving, relapse management and crisis intervention planning.	Generic, Inpatient	Cross- Sectional, Qualitative	26 individuals diagnosed with Bipolar Disorder; 33 relatives: 12 mothers, 13 fathers, 5 spouses, 1 Aunt, 1 cousin, 1 grandmother.	Semi-structured interviews
15 16 17 18	UK (England), English, 2005 [108]	Journal Article	To obtain feedback from couples and families on various aspects of the systemic therapy service and suggestions for service improvement.	Systemic Psychotherapy. Milan systemic and narrative based approaches.	Specialised (Systemic Therapy Service), Outpatient	Cross- Sectional, Mixed methods	25 couples and families receiving systemic therapy for psychotic, personality, anxiety and depressive disorders.	a) Observation b) Clinical interviews c) Questionnaire (rating responses)
19 20 21				model of Behavioural Family Therapy; $CBT = Cognitivealth Nurse; OT = Occupational Therapist; SW = Social W$		nerapy; FI = Fam	ily Intervention; <i>CP</i> = Clinical	
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## PRISMA 2009 Checklist

4 5 Section/topic 6	#	Checklist item	Reported on page #
7 TITLE			
9 Title	1	Identify the report as a systematic review, meta-analysis, or both.	1
12 Structured summary 13 14	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	2-3
17 Rationale	3	Describe the rationale for the review in the context of what is already known.	4-5
1 <del>0</del> 19 Objectives 20	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	5
22 23 Protocol and registration 24 25 26 27	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	Protocol was uploaded as a supplementary file
28 Eligibility criteria 29	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	6
30 Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	5-6
33 Search 34 35 36 37 38 39	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	5-6. Database search strategy was uploaded as a supplementary file.
40 Study selection 41 42 43	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	5-7. Figure 1 (PRISMA flow Diagram)
<sup>44</sup> Data collection process 45 46	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators. For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml	7-8
47 48 49			

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## PRISMA 2009 Checklist

Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	7-8
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	N/A (See strengths and limitations, page 16)
2 Summary measures 3 4	13	State the principal summary measures (e.g., risk ratio, difference in means).	7 (Methods of analysis paragraph)
6 Synthesis of results 7	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I <sup>2</sup> ) for each meta-analysis.	7 (Methods of analysis paragraph)
9		Page 1 of 2	
2 Section/topic	#	Checklist item	Reported on page #
4 Risk of bias across studies 5 6 7 8	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	N/A (See strengths and limitations, page 16)
9 Additional analyses 0 1 2 3	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	N/A (See strengths and limitations, page 16)
6 Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	Page 8 and Figure 1
Study characteristics 18 For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up p and provide the citations.		Page 8-9 and Supplemetary Table 1	
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## PRISMA 2009 Checklist

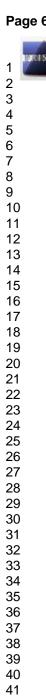
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	N/A (Data analysed using a theoretical thematic analysis approach)
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	N/A (Data analysed using a theoretical thematic analysis approach)
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	N/A (See strengths and limitations, page 16)
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	N/A (See strengths and limitations, page 16)
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	14-15, 16-17
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	15-16
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	16-18
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	18

46 From: Moher D, Liberati A, Tetzlaff J, Altman DG, The BRISMA General Science (2009) Proferred (Bengeing Henry for Switching Beviews and Meta-Applying: The PRISMA Statement. PLoS Med 6(6): e1000097. 47 doi:10.1371/journal.pmed1000097

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