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Why Involve Families in Acute Mental Health Care? A Collaborative Conceptual Review

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Complete List of Authors:	Dirik, Aysegul; Queen Mary University of London, Unit for Social and Community Psychiatry Sandhu, Sima; Queen Mary University of London, Unit for Social and Community Psychiatry Giacco, Domenico; Queen Mary University of London, Unit for Social and Community Psychiatry; East London NHS Foundation Trust Barrett, Katherine; Queen Mary University of London, (Patient/carer researcher, supported to participate at QMUL) Bennison, Gerry; Queen Mary University of London, (patient/carer researcher, supported to participate at QMUL) Collinson, Sue; Queen Mary University of London, (Patient/carer researcher, supported to participate at QMUL) Priebe, Stefan; Queen Mary University of London, Unit for Social and Community Psychiatry
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3 **Why Involve Families in Acute Mental Health Care? A Collaborative Conceptual**
4 **Review**

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6 Aysegul Dirik¹, Sima Sandhu¹, Domenico Giacco^{1,2}, Katherine Barrett³, Gerry Bennison³, Sue
7 Collinson³, Stefan Priebe¹.

8
9 ¹ Unit for Social & Community Psychiatry, (WHO Collaborating Centre for Mental Health
10 Services Development), Queen Mary University of London, United Kingdom

11 ² East London NHS Foundation Trust, United Kingdom

12 ³ Service User/Carer Researcher, supported to participate at ¹ (Queen Mary University of
13 London)

14
15 **Corresponding author:**

16
17 Aysegul Dirik

18 a.dirik@qmul.ac.uk

19 +44 (0)20 7540 4380 ext.2330

20
21 Unit for Social & Community Psychiatry, (WHO Collaborating Centre for Mental Health
22 Services Development), Queen Mary University of London, United Kingdom.
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ABSTRACT

Objectives: Family involvement is strongly recommended in clinical guidelines but suffers from poor implementation. To explore this topic at a conceptual level, a multidisciplinary review team including academics, clinicians and individuals with lived experience undertook a review to explore the theoretical background of family involvement models in acute mental health treatment and how this relates to their delivery.

Design: A conceptual review was undertaken, including a systematic search and narrative synthesis. Included family models were mapped onto the most commonly referenced underlying theories: the diathesis-stress model, systems theories and postmodern theories of mental health. Common components of the models were summarised and compared. Lastly, a thematic analysis was undertaken to explore the role of patients and families in the delivery of the approaches.

Setting: General adult acute mental health treatment.

Results: Six distinct family involvement models were identified. Findings indicated that despite wide variation in the theoretical models underlying family involvement models, there were many commonalities in their components. Thematic analysis of the role of patients and families identified several issues for implementation. This included potential harms, such as imposing linear “patient-carer” relationships and the risk of coercion.

Conclusions: We conclude that future clinical practice may benefit from more discussion about the similarities and differences of family involvement models and how they might be experienced by patients and families.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- We included distinct family involvement models used internationally in acute mental health treatment.
- We explored the role of underlying theories and potential risks of harm, both of which may impact implementation.
- Our multidisciplinary team included the active contribution of people with lived experience of acute mental health treatment as well as clinicians and academics.
- Broadly mapping across models means we did not include an exhaustive list of every single variation of family involvement in acute treatment.
- The identified models were originally developed in various Western mental health settings, which might not reflect the theoretical frameworks of non-Western settings.

BACKGROUND

Practically all mental health policies and guidelines suggest some form of family, friend or carer involvement in patients' mental health care (hereon abbreviated to "family involvement"). The potential benefits of this for patients are well documented, including relapse prevention and reduced hospital stays.[1,2] Despite growing consensus in policy toward family-inclusive services, in reality, audits consistently highlight poor implementation rates.[3] This problem is well documented: over decades of research, frustrations have been expressed about the difficulties of implementing family involvement into routine psychiatric care.[4,5]

To complicate matters, the reason for conducting family involvement in the first place cannot be traced to a single school of thought or point in time. Socio-political events, such as the deinstitutionalisation of mental health services and early theories of mental illness have meant that families often felt both blamed for mental health problems as well as being given the responsibility of providing support. Family advocacy groups have pushed for policy changes towards recognising the support that families provide, and the burden that can be associated with this.[6] Alongside this, multiple family involvement models have emerged based on divergent theories of the nature of mental health problems.

The use of family involvement models can vary highly between services.[7,8] Evidence is emerging of a lack of shared understanding of what constitutes appropriate family involvement and how to best incorporate it into services [9]. Such discord is problematic, as it can impact staff attitudes and the general organisational culture toward family work.[10] This, in turn, has implications for resource allocation and intervention delivery, particularly if there is disagreement about the aim or value of conducting it.[11,12]

A recent review by members of our team identified multiple barriers to the implementation of family involvement at the individual, team and organisational level.[13] These barriers were common across intervention models and international settings. A particularly challenging setting is acute treatment, which typically involves admission to hospital for inpatient treatment or a crisis intervention in the community. Clinician reports indicate numerous difficulties in implementing family involvement in these contexts, which are often characterised by a strong focus on risk reduction and crisis management.[14]

Revisiting the concepts underlying family work seems timely as it may bring us a step closer to understanding how to implement it in a way that is in keeping with the values of mental health organisations, users of their services and families. This review seeks to explore the diversity across different family involvement models and to consider how their theoretical backgrounds might impact on how they are delivered and received today. We investigated the following questions:

- (1) Which family involvement models are used in general adult acute mental health settings?
- (1) What is the theory or rationale underlying family involvement models?
- (2) What are the components of the models?
- (3) What is the role of patients and family in the delivery of the models?

METHOD

For this review, we did not aim to produce an exhaustive list of every existing family involvement model. Instead, we set out to find distinct approaches that represented the

1
2
3 diversity of the models that are used today. A conceptual review,[15] which enables the
4 exploration of the breadth of concepts in a given area was considered the most appropriate
5 methodology to answer these research questions.[16-19] This review was pre-registered on
6 PROSPERO (CRD42016032749).
7

8 **Search Strategy and Selection Criteria**

9

10 A wide search strategy was employed, including a systematic search of electronic databases
11 (Embase, MEDLINE, PsycINFO, BNI, CINAHL and AMED) for descriptors of “family/carers”
12 “mental health” “model/approach” and “setting” and hand searches (see appendix one). AD
13 conducted the searches in consultation with SS and experts in the field. As the searches and
14 analyses were iterative, the chosen key models were finalised during the first stage of
15 analysis.
16

17 We included (1) key texts containing an original description of a family involvement model
18 that (2) referred to the management of an acute mental health situation or the treatment of
19 “severe mental illness” that could be started during the acute phase (3) with a clear
20 description of how families are involved in the patient’s treatment and (4) the primary focus
21 was general adult mental health (ages 18 - 65).
22

23 Papers were excluded if (1) the word “carer” was being used to refer to paid staff members,
24 (2) the primary focus was on specialist services, (3) they were a description of a family
25 therapy model rather than a programme designed for family involvement in acute mental
26 health treatment or (4) it was not possible to obtain an English-language description,
27 although non-English texts were translated whenever possible.
28

29 **Data Analysis**

30

31 A multidisciplinary review team was formed to minimise biases in the searches and
32 analyses.[15] This composed of the lead researcher (AD, a doctoral researcher), a research
33 psychologist (SS), two clinical/academic psychiatrists (DG and SP), three individuals with
34 lived experience of acute mental health treatment, either as patients or as family members
35 (KB, GB and SC) and a clinical nurse manager, who also has research experience (PM).
36 The review team worked most closely on steps two and three below.
37

38 A narrative synthesis was conducted to reach a thorough conceptual understanding of family
39 involvement models.[20] The steps described below were highly iterative:
40

41 1. To develop a preliminary synthesis, found texts were clustered into categories of family
42 involvement models. The clustered groups were expanded and collapsed until the family
43 involvement models were broadly similar within each group and sufficiently different from the
44 other groups. Then, the key texts were identified within each group by reference screening,
45 citation checking and snowballing to find original descriptions of the approach. The final
46 inclusion decision was made after discussions with colleagues and experts in the field.
47

48 Alongside this, the theoretical references of the models were identified by extracting the
49 change processes and reasons for intervention development described in the texts, as well
50 as reference screening, reading widely around the subject area and consulting experts. The
51 chosen family involvement models were mapped on to the identified theories.
52

53 2. Components of the included studies were identified by extracting authors’ descriptions of
54 how the model is carried out and clustering the text into similar methods. Similarities and
55 differences were then compared across the models.
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3. We explored the role of patients and carers within and between the models using thematic analysis.[21] A selection of family involvement models were examined in depth, ensuring there was representation across the identified theoretical references. Analysis of the emerging key themes was conducted iteratively after multiple reflective discussions.

4. As well as utilising our own multidisciplinary review teams, several measures were taken to ensure robustness of the synthesis. This included numerous consultations with a wider team of around 30 researchers, an expert in Family Intervention, two service user research groups (SUGAR, the Service User Group Advising on Research; and SURF, the North London Service User Research Forum), and a Social Psychiatry expert academics meeting. The ROBIS (Risk Of Bias In Systematic reviews) tool was used to guide our methodology, although quality assessment of the included studies themselves was not considered appropriate for this review of concepts.[22]

RESULTS

The analysis was built up at each stage from (1) identifying distinct models (2) mapping the models to their theoretical references (3) comparing the model components and (4) exploring the role of patients and carers in the delivery of the approaches.

1. Key models

We identified six distinct family involvement models from sixteen key sources (table 1). This included four key family psychoeducation models, which were clustered due to the similarity of their underlying approach. The PRISMA flow diagram (figure 1) depicts our selection process.[23]

[Fig 1: Study selection]

Model	Country	Description
<i>Calgary Family Assessment and Intervention Model</i> [24]	Canada	A family nursing intervention whereby nurses in acute care focus on a cognitive, behavioural or affective domain in the family to intervene in. Systemic tools such as genograms and circular questioning are often utilised to instigate change in the family system.
<i>ERIC (Equipe Rapide d'Intervention de Crise, France)</i> [25]	France	Nurses, doctors and psychologists work together as a large multidisciplinary team in a mobile service. Brief psychotherapy is provided, usually in the patient's home, with the aim of "enveloping" (containing) the crisis. There is strong emphasis on the role of communication and the competence of the family unit to deal with future crises.
<i>Family Psychoeducation Models</i> [26-31]	UK, USA	The most widely used model globally, developed from research into the role of family communication in relapse. Specialist teams provide a package of support including at least (1) an educational component about the patient's diagnosis and the recommended treatment; (2) problem solving and/or communication training to simplify communication for the patient and (3) emotional support for the family.

1 2 3 4 5 6 7 8 9	<i>Family Systems Approach (SYMPA)</i> [32-34]	Germany	All staff across disciplines are trained to assess and treat patients within a systemic framework. This includes changing language use to less medicalised terms. Staff are also trained as “negotiators” between the patient and the organisation about matters such as medication and compulsory measures.
10 11 12 13 14 15 16 17	<i>Open Dialogue</i> [35-37]	Finland	A multidisciplinary mobile crisis team attend the patient’s home within a short time from referral. Meetings including the patient’s wider social network take place daily, and continue until a “joint understanding” is reached of the patient’s distress. The process of listening and responding is considered central in reducing the patient’s distressed state.
18 19 20 21 22 23 24	Somerset Model[38,39]	UK	Service-wide approach, developed to address policy and advocacy-led calls for more family-inclusive services. All families are offered an initial needs assessment and information about the service, and may be referred to more intensive provision.

Table 1: Family involvement models in acute mental health care

2. Theory mapping

We then explored how the models relate to their most commonly cited theoretical influences, which included systems theory, the diathesis-stress model and postmodern theories (see figure 2).

[Fig. 2: The placement of family involvement models within the diathesis-stress, systems and postmodern theories.]

Systems Theories

Systems theories (e.g. General Systems Theory and Cybernetics)[40-42] are commonly used frameworks for broadly understanding how all systems function and the importance of interactions in those systems. In psychiatry, a major application of these theories has been systemic family therapy.[43-45] Here, the broad principles posit that there is an issue within the family system and that one person within this becomes the designated “patient” presented to services. The professional’s role is to work with the whole family to influence the processes that contribute to the patient’s mental state.

A minority of the examined models offer traditional systemic family therapy as a supplementary, intensive service for particular families.[32,33,35] However, the general influence of systems theories is substantial across the models. Historically, whilst some models were developed in part as a reaction to the perceived “blaming” attitude of systemic family therapy,[26,28,29] others used systemic principles as a guideline to set-up family-inclusive services.[25,32-34,38,39] Notably, the majority of models utilise systemic techniques in their everyday practice, such as constructing genograms (social network diagrams) to understand the patient’s social environment[24,32,38,39] and using therapeutic techniques such as circular questioning.[28]

The Diathesis-Stress Theory

1
2
3 The diathesis-stress model posits that people with schizophrenia have an underlying
4 physical vulnerability to developing symptoms, the risk of which only manifests if the person
5 experiences excessive environmental stress.[46] Research into potential environmental
6 stressors highlighted several concepts of harmful (or helpful) communication patterns within
7 families.[47] The most widely accepted measure today is “Expressed Emotion” (“EE”), which
8 suggests that levels of *hostility, criticism, overinvolvement, and warmth* can affect a person’s
9 likelihood of relapse ”).[47,48]

10
11 Based on this theory, multiple family involvement models were developed to address the
12 underlying biological causes of schizophrenia by using medication as well as providing
13 “psychoeducation” to families to teach them the diathesis-stress model and reduce stressful
14 “high EE” communication that could exacerbate symptoms. [26-31] Later, these models were
15 developed to include other mental and physical health conditions [49-52] and alternative
16 modes of delivery, including mobile crisis teams [53] and online interventions. [54,55]

17
18 Whilst the clearest influence of the diathesis-stress theory is on family psychoeducation
19 models,[26-31] arguably its elements exist in all models that take place within a medical
20 system. For example, almost all of the models routinely recommended medication along with
21 a social intervention (e.g. [32-34]).

22 23 *Postmodern Theories*

24
25 Postmodern approaches to mental health are often critical of commonly-accepted narratives
26 of “mental illness”. [56] Influential theories within this sphere include social constructionism
27 and constructivism, which broadly posit that mental health problems only exist in social
28 contexts and so their solutions can only emerge within those contexts.[57-59] Whilst the rise
29 in popularity in the 1960s is well documented (e.g. [57,58,60]), these viewpoints were not
30 translated to widely used family involvement models, and largely fell out of favour for more
31 medically focused approaches. However, some models developed from postmodern and
32 systemic ideas, often as a reaction to more medical theories.[24,32-37]

33
34 Whilst pure postmodernism rejects biological explanations, these models took a more
35 integrated approach, incorporating postmodern theories and practices (e.g. [61-63]) into
36 existing medical systems. Common features included strong emphasis on the wider social
37 context [35-37] and prominence given to individual narratives and explanations [24,35,36]
38 rather than imposing an “absolute truth” such as a set diagnosis or highly structured
39 treatment model.

40 41 **3. Synthesis of the components of the approaches**

42
43 Considering the rich and divergent theoretical background of family involvement models, we
44 examined how these theories related to the components of the models. The most common
45 components across the models are summarised in table 2.
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	Communication / Language Use	Joint Decision-Making	Support For The Family	Wider Social Network	Medication Use	Specialist Teams/Staff	Whole Systems Approach
Calgary Family Assessment and Intervention Model [24]	√√	√√	√√	√	√	-	√√
ERIC (Equipe Rapide d'Intervention de Crise) [25]	√√	√	√√	√	√	-	√√
Family Psychoeducation Models [26-31]	√√	√	√√	-	√√	√√	-
Family Systems Approach (SYMPA) [32-34]	√√	√√	√	√	√	-	√√
Open Dialogue [35-37]	√√	√√	√	√√	√	-	√√
Somerset Service Model [38,39]	√	√	√√	√	√	-	√√

Table 2: Common components of family involvement models (key: √√ Strongly emphasised in model; √ Present in the model, not a key feature; - Relatively less or no emphasis)

Communication/Language Use

Communication and language use were strongly emphasised across all models. Models adhering to the diathesis-stress theory intervened in EE communication as a tool in relapse prevention.[47,48] In Open Dialogue and ERIC, whilst the theoretical basis was very different, the dialogue between and within participants was theorised as the main driver of change.[25,35-37] Systemic approaches such as the Calgary model trained staff in communication to improve families' service experience [24] whilst in SYMPA staff were trained to avoid diagnostic labels, as they could disempower patients and encourage a "psychiatric career" identity.[32,33]

Joint Decision-Making and the Role of Experts

1
2
3
4 All the models emphasised the need to make decisions jointly, although the emphasis on
5 experts differed. Models based on the diathesis-stress theory, which are more medical in
6 nature, emphasised the importance of experts who provide “*information, advice and*
7 *guidance*” [28]. However, this approach existed in other models, but was not acknowledged
8 as openly. Other models “*incompatible*” with “*the illness concept inherent in the idea of*
9 *vulnerability and the strong focus on compliance with psychopharmacological treatments*”
10 (p.377, [33]) still described how clinicians needed to “*negotiate*” various aspects of the
11 treatment with the patient and their family.[32-34] Postmodern-influenced models minimised
12 professionals’ role in treatment decisions, and made all clinical decisions jointly with the
13 patient and their wider social network. This often meant that the professionals had to
14 “tolerate uncertainty” in the treatment process.[35-37]
15

16 *Support for the Family Themselves*

17
18 Some models were developed directly in response to families’ stated needs for support and
19 involvement.[27,28,38,39] This could for example prevent the build-up of problems which
20 could manifest as poor communication.[27] More systemic or postmodern influenced models
21 were less focused on family support, and rather saw the involvement of the patient’s wider
22 social network as a necessary tool in understanding their social context.[32-34]
23

24 *Wider Social Network Involvement*

25
26 The involved “family” differed across the models. Psychoeducation models generally
27 focused on the people the patient lives with (and therefore interacts with the most), meaning
28 it was largely aimed towards parents and partners. [26-31] This was sometimes a deliberate
29 decision based on previous lack of utility when involving extended relatives and friends. [29]
30 Whilst some systemic models also referred to the family in this context [25] others used the
31 term “family” more widely to refer to any members of the patient’s “*problem determined-*
32 *system*”.[34] Open Dialogue, which focuses heavily on interactions within the wider social
33 network placed importance on all its members, including friends, family, neighbours and
34 colleagues.[35-37]
35

36 *Medication Use*

37
38 Approaches that derive more from the diathesis-stress model considered medication to be
39 an essential component and the family were often seen as a core resource to help with
40 maintaining adherence.[26,29-31] Whilst the SYMPA model favoured a systemic
41 understanding of the patient’s situation, the importance of “negotiation” with the patient
42 regarding medication was emphasised.[32-34] Other systemic and postmodern-influenced
43 models placed less emphasis on its use.[24,25] The greatest variation was in Open
44 Dialogue, as patients were not given medication at the outset. If their condition did not
45 improve, they were offered a low dose, with the aim to taper or discontinue its use over
46 time.[35-37]
47

48 *System organisation*

49
50 Finally, a major area of difference was the way the service was organised to deliver family
51 involvement. Models based on the diathesis-stress theory usually required a small group of
52 staff members to be trained as family involvement specialists who could manage the
53 complexities of patient-family work.[26-31] Conversely, systemic models required whole
54 teams to be trained in the principles of family involvement.[24,32-39]
55

56 **4. The role of patients and families**

For the final research question, a thematic analysis[21] was conducted on the descriptions of the role of patients and families in the delivery of the models (summarised in table 3).

Theme	Subthemes
1. Families Are a Resource	
2. Linear Roles and Relationships	2.1. <i>There is a “patient” and a “carer”</i> 2.2. <i>Families want to help</i> 2.3. <i>Family involvement is always beneficial</i>
3. Risk of Identity Loss	
4. Implementation vs. Choice	

Table 3. Themes and subthemes relating to the role of patients and families in family involvement models

1. Families Are a Resource

Families were conceptualised as a resource in a number of ways. They were often seen as “*potentially competent partners*” ([64] cf. [35]) in the stabilisation phase of the patient and adherence to clinical procedures.[25-27,29,31] They were also perceived as a source of information about the patient’s situation - whether directly or by observation.[26,32,33]

However, it was unclear whether family members were given the opportunity to refuse involvement whilst acknowledging the potential feelings of guilt that can emerge from this. Success of a model often seemed to depend on the willingness of the family to accept their “helpful” or “carer” role and to engage with the techniques led by the professionals. Often, there were descriptions of how to engage unwilling family members).[26,31,35,36]

2. Linear Roles and Relationships

2.1. *There is a “patient” and a “carer”*: The relationship between the family and the individual accessing services was presented linearly, unless it was referring to co-dependency.[28] Even in systemic approaches that had circular causation as a theoretical reference, there was a clear, unidirectional “carer” and “patient” role. [24,25,32-34] The possibility of reciprocal support or a more egalitarian or independent relationship was not explicitly described in the examined models.

2.2. *Families want to help*: Related to this, it was generally assumed that families either want involvement in the patient’s treatment, or do not want it because they have been let down by professionals in the past.[26,38,39] The concept that families might care for a relative but not want to feel responsible for their treatment was not explored.

2.3. *Family involvement is always beneficial*: Moreover, whilst it was acknowledged that not everyone has supportive family members and that some relationships might be complicated, it was generally assumed that the involvement of family would be beneficial.[31,35,36] The potential harms of involvement, as described next were often not explored.

Risk of Identity Loss

Considering the inherent vulnerability of being an individual in acute care, the positive and negative implications of involving others seemed greater. Clearly, family and friends could be a source of comfort and support in a difficult setting. However, sharing one’s private information in a setting where they are the “patient in need” could also risk altering their roles and relationships after they left acute treatment. In approaches with a wider social network approach, this potentially carried a higher risk. For example, colleagues may be invited to

1
2
3 treatment meetings.[35-37] Whether the patient in crisis could make a fully informed decision
4 about the consequences of this and the possible impact this could have when they return to
5 work was not discussed.

6
7 Moreover, a general lack of accounts from patients themselves across the models meant
8 that the “patient” could sometimes be described as a passive recipient of the interventions.
9 Examples of individuals taking a more active role included psychoeducation that enlisted
10 patients to share their own accounts[26] and patients being a core part of joint decision-
11 making.[35-37]

12 13 *Implementation vs. Choice*

14
15 Considering these points, we contemplated the role of patient choice in family involvement
16 and how the structure of service organisation might affect this. If a whole service is set up to
17 operate on the principles that family involvement is fundamental to psychiatric treatment, this
18 makes it more likely to be implemented, as all staff are fully trained in facilitating it.[24,32-39]
19 However, this also has greater potential to weaken the patient’s voice in the matter, making
20 them feel pressured to involve others in a process they might have preferred to remain
21 private. Conversely, if there are only specialist family involvement teams within a larger
22 system, this can soon become an underused “niche” service. In this case, the specialist
23 team must rely on external factors such as managers and other colleagues seeing value in
24 their approach, providing resources and collaborating to identify and refer “suitable” families
25 to the service, all of which can result in lower implementation.[13,26-31]

26 27 **DISCUSSION**

28
29 This review broadly identified key family involvement models in acute mental health
30 treatment and considered how their theoretical references are related to their delivery. From
31 this, we considered how their implementation might impact patients and families. Despite
32 major theoretical differences, we found many similarities in the components of the models,
33 which raised the question: what is the intended aim when involving families and is it
34 important to specify this? Namely, should all models be considered the same or is the
35 theoretical basis an important aspect of delivery? Perhaps, as has been suggested for
36 individual psychotherapy, nonspecific factors determine the usefulness of the chosen
37 model.[65] However, it may be important to place the model within its wider theoretical
38 context to aid staff training and understanding.

39
40 For example, there may be a conflict in how staff should conceptualise the “patient” and
41 “family” roles and relationships. MacFarlane highlights how clinicians might struggle to be
42 simultaneously family-positive and inclusive despite being taught that they are at least
43 partially responsible for the patient’s problems.[66] Acknowledging these tensions and
44 finding a way to integrate divergent world views may increase the likelihood of implementing
45 family involvement more consistently across services.

46
47 It is also important to consider that overall, a significant aspect of implementation is how well
48 a model fits with a service’s existing values.[67] Family psychoeducation is most strongly
49 aligned with the existing biopsychosocial medical model, and this might be one reason why it
50 fits more easily into existing services than postmodern or systemic models. The
51 fundamentals of the latter approaches might be harder to train clinicians who have primarily
52 been taught the biopsychosocial model, and to obtain resources through regular funding
53 structures which prioritise medically-focused clinical outcomes.

54
55 In considering implementation, the importance of patient and family experience should also
56 be emphasised. For example, the notion of implementation versus choice emerged as a
57 significant consideration in our review. Too much focus on system-wide implementation
58
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1
2
3 could mean more likelihood of a patient feeling coerced into involving others during what is
4 preferred to be a private process.
5

6 This is of particular importance considering the potential harmful impacts of assuming
7 individuals hold particular roles in their relationship. For example, a mother having a mental
8 health crisis might not wish for her son to be present as a “carer” in her most acute phase,
9 even if he is of adult age. This risks not only taking away her role as a person who holds
10 authority and respect (a “parent”) but it might impact on the dynamics of their relationship
11 after the acute episode has subsided. This notion corresponds with Goffman’s theories of
12 the risk of identity loss in inpatient settings.[60]
13

14 Our review also indicated the potential for family members to be disempowered by being
15 viewed as a resource for services. This point was recently raised by Meijer and colleagues,
16 who highlight the tension of being imposed the role of “carer” whilst having one’s own goals
17 and needs to attend to.[68] Rugkåsa’s comprehensive review of elements of coercion in
18 caring also makes the point that families may wish to be less involved in the care of their
19 relative but fear the consequences of doing so.[69]
20

21 It is important to note here that many families wish to have significantly more involvement,
22 particularly in crisis contexts.[70,71] However, it highlights the challenges of accommodating
23 diverse needs in an already complex service setting. Overall, the offer of family involvement
24 requires a delicate balance on the part of service leaders to support implementation whilst
25 maximising patients’ and families’ decision-making in the process.
26

27 **Strengths and Limitations**

28
29 This review has a number of strengths and limitations to consider. To our knowledge this is
30 the first conceptual review that has actively included people with lived experience of mental
31 health services alongside academics and clinicians in the review team. This has allowed for
32 in-depth integrations of personal and professional experiences of family involvement. This
33 has contributed to a deeper understanding of not just the concepts present in each model,
34 but also what is *not* explained. From the latter, potential problems in the delivery of
35 interventions were revealed. Research into patient safety emphasises the benefits of
36 involving people with lived experience in identifying unknown latent harms.[72]
37

38 Although we conducted a systematic search, our findings are by no means an exhaustive list
39 of all existing family involvement models. We avoided this for pragmatic reasons: in practice,
40 the implementation of family involvement models can vary greatly, resulting in an infinite
41 number of ways each component can be delivered. Investigating these infinite nuances will
42 not necessarily lead to a better understanding of the field as a whole. Instead, a broad
43 understanding of the diversity of the models that exist, and their common concepts, signifies
44 how family involvement is delivered in most settings.
45

46 Finally, due to the emphasis on published articles and manuals, the majority of literature was
47 based in Europe, the USA and Australasia, or what is often referred to as the “Western”
48 medical system. This common problem can impact how relevant the results are cross-
49 culturally.[73] However, when screening articles we struck by how globalised family
50 involvement approaches had become, particular the adaptation of family psychoeducation to
51 a number of international contexts [74-76]. How well this approach integrates with existing
52 belief systems is a matter for another enquiry.
53

54 **Conclusions**

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56 Despite strong links to diverse theoretical perspectives and socio-political events, there are
57 many commonalities in the models used in family involvement. We encourage further
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discussion of these differences and similarities when considering its implementation in acute settings, particularly in light of the diverse needs of patients, families and professionals.

For peer review only

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COMPETING INTERESTS

None declared.

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DATA SHARING STATEMENT

No additional data are available.

AUTHORS' CONTRIBUTIONS

AD designed the study, conducted searches and data extraction (in consultation with SS and SP), led on the analysis and prepared the manuscript. All authors contributed to the analysis, critically reviewed the paper and approved the final manuscript. SP and SS provided overall guidance and supervision for the study.

REFERENCES

- 1 Pharoah F, Mari J, Rathbone J, *et al*. Family intervention for schizophrenia. *Cochrane Database of Systematic Reviews* 2010;**12**.
- 2 Garety P, Pilling S, Bebbington P, *et al*. Psychological treatments in schizophrenia: I. Meta-analysis of family intervention and cognitive behaviour therapy. *Psychol Med* 2002;**32**:763–82. doi:10.1017/S0033291702005895
- 3 Ince P, Haddock G, Tai S. A systematic review of the implementation of recommended psychological interventions for schizophrenia: Rates, barriers, and improvement strategies. *Psychology and Psychotherapy: Theory, Research and Practice* Published Online First: 5 November 2015. doi:10.1111/papt.12084
- 4 Macfarlane MM. *Family Therapy and Mental Health*. Routledge. 2013.
- 5 Mairs H, Bradshaw T. Implementing family intervention following training: what can the matter be? 2005;**12**:1–7. doi:10.1111/j.1365-2850.2005.00871.x
- 6 Worthington A, Rooney P. The Triangle of Care; Carers included: A guide to best practice in acute mental health care. 2010:1–32.
- 7 Hofmann SG, Tompson MC. *Treating Chronic and Severe Mental Disorders: A Handbook of Empirically Supported Interventions*. Guilford Press. 2002.
- 8 Eisler I. A rose by any other name. *Journal of Family Therapy*. 2005.
- 9 Kavanagh DJ. What the Problem May Be With Family Intervention ... and With Dissemination More Generally: A Commentary. *Australian Psychologist* 2016;**51**:69–72. doi:10.1111/ap.12205
- 10 Fadden G, Birchwood M, Lefley H, *et al*. British models for expanding family psychoeducation in routine practice. *Family interventions in mental illness: International perspectives* 2002:25–42.
- 11 Brooker C, Butterworth C. Working with families caring for a relative with schizophrenia: the evolving role of the community psychiatric nurse. *International Journal of Nursing Studies* 1991;**28**:189–200.
- 12 Brent BK, Giuliano AJ. Psychotic-spectrum illness and family-based treatments: a case-based illustration of the underuse of family interventions. *Harvard Review of Psychiatry* 2007;**15**:161–8.
- 13 Eassom E, Giacco D, Dirik A, *et al*. Implementing family involvement in the treatment of patients with psychosis: a systematic review of facilitating and hindering factors. *BMJ Open* 2014;**4**:e006108–8. doi:10.1136/bmjopen-2014-006108
- 14 Fadden G. Overcoming barriers to staff offering family interventions in the NHS. In: *A Casebook of Family Interventions for Psychosis*. John Wiley and Sons. 2009.
- 15 Lilford RJ, Richardson A, Stevens A, *et al*. Issues in methodological research: perspectives from researchers and commissioners. *Health Technology Assessment* 2001;**5**. doi:10.3310/hta5080

- 1
2
3 16 Priebe S, Dimic S, Wildgrube C, *et al.* Good communication in psychiatry – a
4 conceptual review. *European Psychiatry* 2011;**26**:403–7.
5 doi:10.1016/j.eurpsy.2010.07.010
6
7 17 Chow WS, Priebe S. Understanding psychiatric institutionalization: a conceptual review.
8 *BMC Psychiatry* 2013;**13**:1–1. doi:10.1186/1471-244X-13-169
9
10 18 Priebe S, Omer S, Giacco D, *et al.* Resource-oriented therapeutic models in psychiatry:
11 conceptual review. *The British Journal of Psychiatry* 2014;**204**:256–61.
12 doi:10.1192/bjp.bp.113.135038
13
14 19 Leamy M, Bird V, Le Boutillier C, *et al.* Conceptual framework for personal recovery in
15 mental health: systematic review and narrative synthesis. *The British Journal of*
16 *Psychiatry* 2011;**199**:445–52. doi:10.1192/bjp.bp.110.083733
17
18 20 Popay J, Roberts H, Sowden A, *et al.* Guidance on the conduct of narrative synthesis in
19 systematic reviews. 2006.
20
21 21 Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in*
22 *Psychology* 2006;**3**:77–101. doi:10.1191/1478088706qp063oa
23
24 22 Whiting P, Savović J, Higgins JPT, *et al.* ROBIS: A new tool to assess risk of bias in
25 systematic reviews was developed. *Journal of Clinical Epidemiology* 2016;**69**:225–34.
26 doi:10.1016/j.jclinepi.2015.06.005
27
28 23 Moher D, Liberati A, Tetzlaff J, *et al.* Preferred Reporting Items for Systematic Reviews
29 and Meta-Analyses: The PRISMA Statement. *Ann Intern Med* 2009;**151**:264–9.
30 doi:10.7326/0003-4819-151-4-200908180-00135
31
32 24 Wright LM, Leahey M. *Nurses and Families*. F A Davis Company 2012.
33
34 25 Zeltner L, Ampelas J-F, Mallat V, *et al.* Prise en charge de crise et enveloppe
35 langagière. *Thérapie Familiale* 2002;**Vol. 23**:357–66. doi:10.3917/TF.024.0357
36
37 26 Falloon IRH. *Family care of schizophrenia: a problem-solving approach to the treatment*
38 *of mental illness*. Guilford Press New York. 1984.
39
40 27 Leff J, Berkowitz R, Eberlein-Vries R, *et al.* A controlled trial of social intervention in the
41 families of schizophrenic patients. *The British Journal of Psychiatry* 1982;**141**:121–34.
42 doi:10.1192/bjp.141.2.121
43
44 28 Kuipers L, Leff J, Lam D. *Family Work for Schizophrenia*. RCPsych Publications. 2002.
45
46 29 Anderson CM, Reiss DJ, Hogarty GE. *Schizophrenia and the Family*. Guilford Press.
47 1986.
48
49 30 Hogarty GE, Anderson CM, Reiss DJ, *et al.* Family Psychoeducation, Social Skills
50 Training, and Maintenance Chemotherapy in the Aftercare Treatment of Schizophrenia:
51 I. One-Year Effects of a Controlled Study on Relapse and Expressed Emotion. *Archives*
52 *of General Psychiatry* 1986;**43**:633–42. doi:10.1001/archpsyc.1986.01800070019003
53
54 31 Barrowclough C, TARRIER N. *Families of Schizophrenic Patients*. Nelson Thornes. 1992.
55
56 32 Schweitzer J, Ginap C, Twardowski Von J. Training psychiatric teams to do family
57 systems acute psychiatry. *Journal of Family Therapy* 2007;**29**:3–20. doi:10.1111/j.1467-
58 6427.2007.00366.x
59
60

- 1
2
3 33 Schweitzer J, Zwack J, Nicolai E, *et al.* Family systems psychiatry: principles, good
4 practice guidelines, clinical examples, and challenges. *American Journal of*
5 *Orthopsychiatry* 2007;**77**:377–85. doi:10.1037/0002-9432.77.3.377
6
7 34 Haun MW, Kordy H, Ochs M, *et al.* Family systems psychiatry in an acute in-patient
8 setting: the implementation and sustainability 5 years after its introduction. *Journal of*
9 *Family Therapy* 2013;**35**:159–75. doi:10.1111/j.1467-6427.2012.00586.x
10
11 35 Seikkula J, Alakare B, Aaltonen J. Open dialogue in psychosis I: An introduction and
12 case illustration. *Journal of Constructivist ...* Published Online First: 2001.
13 doi:10.1080/10720530125965
14
15 36 Seikkula J, Alakare B, Aaltonen J. Open dialogue in psychosis II: A comparison of good
16 and poor outcome cases. *Journal of Constructivist ...* Published Online First: 2001.
17 doi:10.1080/10720530126129
18
19 37 Seikkula J, Aaltonen J, Alakare B, *et al.* Five-year experience of first-episode
20 nonaffective psychosis in open-dialogue approach: Treatment principles, follow-up
21 outcomes, and two case studies. *Psychotherapy Research* 2006;**16**:214–28.
22 doi:10.1080/10503300500268490
23
24 38 Stanbridge R, Burbach F. Developing family-inclusive mainstream mental health
25 services. *Journal of Family Therapy* 2007;**29**. doi:10.1111/j.1467-6427.2007.00367.x
26
27 39 Stanbridge R, Burbach F. Establishing family inclusive acute inpatient mental health
28 services: a staff training programme in Somerset. *Journal of Family Therapy*
29 2009;**31**:233–49. doi:10.1111/j.1467-6427.2009.00467.x
30
31 40 Bertalanffy Von L. The history and status of general systems theory. *Academy of*
32 *Management Journal* 1972;**15**:407–26.
33
34 41 Wiener N. *Cybernetics Or Control and Communication in the Animal and the Machine.*
35 MIT Press 1961. doi:10.2307/41885113
36
37 42 Ashby WR. *An Introduction to Cybernetics.* London: Chapman & Hall. 1956.
38
39 43 Selvini-Palazzoli M, Boscolo L, Cecchin G, *et al.* *Paradox and counterparadox: A new*
40 *model in the therapy of the family in schizophrenic transaction (tsl., EV Burt).* New York:
41 Jason Aronson 1978.
42
43 44 Haley J, Erickson MH. *Uncommon therapy.* Norton New York. 1973.
44
45 45 Minuchin S. *Families and therapy.* Structural family therapy in theory and practice
46 (Swe.) Harvard University Press. 1974.
47
48 46 Zubin J, Spring B. Vulnerability: A new view of schizophrenia. *Journal of Abnormal*
49 *Psychology* 1977;**86**:103–26. doi:10.1037/0021-843X.86.2.103
50
51 47 Brown GW, Birley JL, Wing JK. Influence of family life on the course of schizophrenic
52 disorders: A replication. *The British Journal of Psychiatry* 1972;**121**:241–58.
53 doi:10.1192/bjp.121.3.241
54
55 48 Vaughn CE, Leff JP. The influence of family and social factors on the course of
56 psychiatric illness. A comparison of schizophrenic and depressed neurotic patients. *The*
57 *British Journal of Psychiatry* 1976;**129**:125–37. doi:10.1192/bjp.129.2.125
58
59
60

- 1
2
3 49 Miklowitz DJ. *Bipolar disorder: A family-focused treatment approach*. Guildford Press
4 2010.
- 5
6 50 Hutchison SD, Steginga SK, Dunn J. The tiered model of psychosocial intervention in
7 cancer: a community based approach. *Psycho-Oncology* 2006;**15**:541–6.
8 doi:10.1002/pon.973
9
- 10 51 Alloway SC, Toth EL. Effectiveness of a group psychoeducation program for the
11 treatment of subclinical disordered eating in women with type 1 diabetes. *Canadian*
12 *Journal of ...* 2001.
- 13
14 52 Garner DM, Rockert W, Olmsted MP. Psychoeducational principles in the treatment of
15 bulimia and anorexia nervosa. ... *for anorexia nervosa ...* 1985.
- 16
17 53 McFarlane WR, Stastny P, Deakins S. Family-aided assertive community treatment: A
18 comprehensive rehabilitation and intensive case management approach for persons
19 with schizophrenic disorders. *New directions for mental health services* 1992;**1992**:43–
20 54.
- 21
22 54 Sin J, Henderson C, Pinfold V, *et al.* The E Sibling Project—exploratory randomised
23 controlled trial of an online multi-component psychoeducational intervention for siblings
24 of individuals with first episode psychosis. *BMC Psychiatry* 2013;**13**:123.
- 25
26 55 Alvarez-Jimenez M, Alcazar-Corcoles MA, González-Blanch C, *et al.* Online, social
27 media and mobile technologies for psychosis treatment: A systematic review on novel
28 user-led interventions. *Schizophrenia Research* 2014;**156**:96–106.
29 doi:10.1016/j.schres.2014.03.021
30
- 31 56 Seikkula J, Aaltonen J, Alakare B, *et al.* *Treating psychosis by means of open dialogue*.
32 The reflective team in action: ... 1995.
- 33
34 57 Laing RD. *The divided self: A study of sanity and madness*. London: Tavistock 1960.
- 35
36 58 Foucault M. *Maladie Mentale Et Psychologie*. Univ of California Press. 1966.
- 37
38 59 Gergen KJ. The social constructionist movement in modern psychology. *American*
39 *Psychologist* 1985;**40**:266–75. doi:10.1037/0003-066X.40.3.266
40
- 41 60 Goffman, E. *Asylums: Essays on the social situation of mental patients and other*
42 *inmates*. AldineTransaction. 1968.
- 43
44 61 Bakhtin MM. *The dialogic imagination: Four essays*. 2010.
- 45
46 62 Bakhtin M, Emerson C. *Problems of Dostoevsky's poetics*. 1993.
- 47
48 63 Moules NJ. Postmodernism and the Sacred: Reclaiming Connection in Our Greater-
49 Than-Human Worlds. *Journal of Marital and Family Therapy* 2000;**26**:229–40.
- 50
51 64 Gleeson JO, Jackson HJ, Stavely HE, Burnett PE. Family intervention in early
52 psychosis. The recognition and management of early psychosis: A preventive
53 approach. 1999.
- 54
55 65 Ahn H-N, Wampold BE. Where oh where are the specific ingredients? A meta-analysis
56 of component studies in counseling and psychotherapy. *Journal of Counseling*
57 *Psychology* 2001;**48**:251–7. doi:10.1037/0022-0167.48.3.251
58
59
60

- 1
2
3 66 McFarlane WR. *Families in the treatment of psychotic disorders*. Harvard Mental Health
4 Letter. 1995.
5
6 67 Greenhalgh T, Robert G, Bate P, *et al*. *Diffusion of innovations in health service*
7 *organisations: a systematic literature review*. John Wiley & Sons 2008.
8
9 68 Meijer E, Schout G, Abma T. Am I My Brother's Keeper? Moral Dimensions of Informal
10 Caregiving in a Neoliberal Society. *Health Care Analysis* 2016;:1–15.
11 doi:10.1007/s10728-016-0313-7
12
13 69 Rugkåsa J. Family carers and coercion in the community. *Coercion in Community*
14 *Mental Health Care: International Perspectives*. Oxford University Press 2016.
15
16 70 Wilkinson C, McAndrew S. "I'm not an outsider, I'm his mother!" A phenomenological
17 enquiry into carer experiences of exclusion from acute psychiatric settings. *Int J Ment*
18 *Health Nurs* 2008;**17**:392–401. doi:10.1111/j.1447-0349.2008.00574.x
19
20 71 Walkup J. Family involvement in general hospital inpatient care. 1997;:51–64.
21 doi:10.1002/yd.23319977307
22
23 72 Wright J, Lawton R, O'Hara J, *et al*. Improving patient safety through the involvement of
24 patients: development and evaluation of novel interventions to engage patients in
25 preventing patient safety incidents and protecting them against unintended harm.
26 *Programme Grants for Applied Research* 2016;**4**:1–296. doi:10.3310/pgfar04150
27
28 73 Berry JW, Poortinga YH, Breugelmans SM, *et al*. *Cross-Cultural Psychology*.
29 Cambridge University Press 2011.
30
31 74 Eker F, Harkin S. Effectiveness of six-week psychoeducation program on adherence of
32 patients with bipolar affective disorder. *Journal of Affective Disorders* 2012;**138**:409–16.
33 doi:10.1016/j.jad.2012.01.004
34
35 75 Chan SW-C, Yip B, Tso S, *et al*. Evaluation of a psychoeducation program for Chinese
36 clients with schizophrenia and their family caregivers. *Patient Education and*
37 *Counseling* 2009;**75**:67–76. doi:10.1016/j.pec.2008.08.028
38
39 76 Hackethal V, Spiegel S, Lewis-Fernández R, *et al*. Towards a Cultural Adaptation of
40 Family Psychoeducation: Findings from Three Latino Focus Groups. *Community Ment*
41 *Health J* 2013;**49**:587–98. doi:10.1007/s10597-012-9559-1
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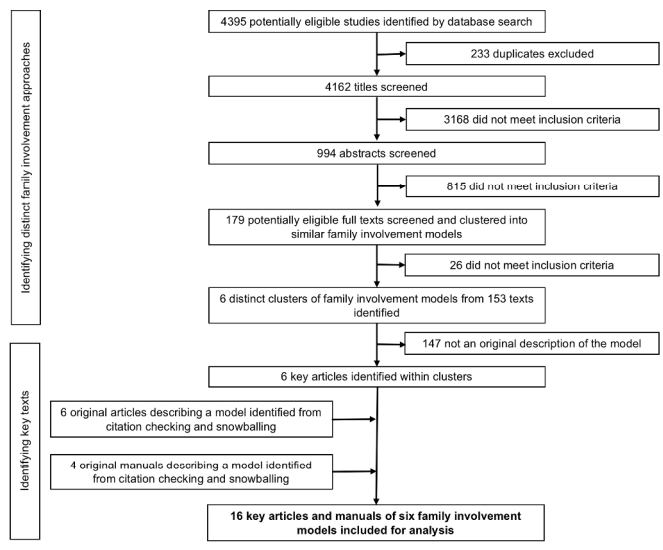


Fig 1: PRISMA flow diagram depicting study selection

338x190mm (225 x 225 DPI)

review only

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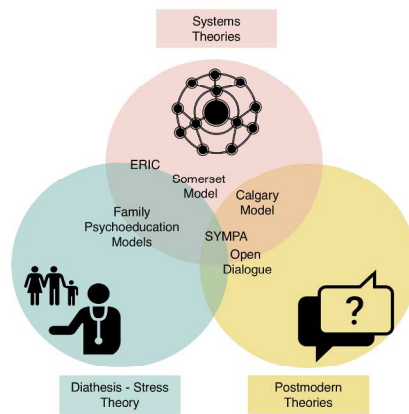


Fig. 2: The placement of family involvement models within the diathesis-stress, systems and postmodern theories

338x190mm (225 x 225 DPI)

review only

Appendix 1: Search Strategy

Embase/MEDLINE

1. 'caregiver'/exp OR 'caregiver' OR carer*:ab,ti OR (social NEXT/2 network*):ab,ti OR famil*:ab,ti
2. 'psychosis'/exp OR 'psychosis' OR 'bipolar disorder'/exp OR 'bipolar disorder' OR 'mental patient'/exp OR 'mental patient' OR (severe* NEXT/2 mental*):ab,ti AND ill*:ab,ti OR ((serious* NEXT/2 mental*):ab,ti AND ill*:ab,ti) OR (service NEXT/1 user*):ab,ti OR (consumer:ab,ti AND mental:ab,ti) OR 'mental disease'/exp OR 'mental disease'
3. 'mental health care'/exp OR 'mental health care' OR 'crisis intervention'/exp OR 'crisis intervention' OR 'involuntary commitment'/exp OR 'involuntary commitment' OR 'inpatient'/exp OR 'inpatient' OR 'psychiatric department'/exp OR 'psychiatric department' OR acute:ab,ti
4. 'medication therapy management'/exp OR 'medication therapy management' OR 'program development'/exp OR 'program development' OR 'patient care planning'/exp OR 'patient care planning' OR 'health services research'/exp OR 'health services research' OR intervention:ab,ti OR involv*:ab,ti OR program*:ab,ti AND ('psychotherapy'/exp OR 'psychotherapy') OR 'psychotherapy'/exp OR 'psychotherapy'
5. #1 AND #2 AND #3 AND #4

PsycINFO

1. DE "Caregivers" OR MM "Social Networks" OR (DE "Family Members" OR DE "Family") OR Carer* OR Famil* OR caregiv*
2. DE "Psychosis" OR DE "Acute Psychosis" OR DE "Affective Psychosis" OR DE "Chronic Psychosis" OR DE "Schizophrenia" OR MM "Bipolar Disorder" OR MM "Cyclothymic Personality" OR MM "Mental Disorders" OR ((Severe* OR serious*) AND Mental* AND Ill*) OR (Service AND User*) OR (Consumer* AND Mental)
3. MM "Involuntary Treatment" OR MM "Psychiatric Hospitalization" OR MM "Psychiatric Hospital Admission" OR MM "Psychiatric Hospital Discharge" OR MM "Psychiatric Hospital Readmission" OR DE "Psychiatric Hospital Admission" OR MM "Psychiatric Units" OR MM "Crisis Intervention" OR acute* OR inpatient
4. DE "Treatment Planning" OR DE "Discharge Planning" OR (DE "Intervention" OR DE "Crisis Intervention" OR DE "Early Intervention" OR DE "Family Intervention" OR DE "Group Intervention") OR (MM "Mental Health Services") OR MM "Program Development" OR involv* OR program* OR interven*
5. #1 AND #2 AND #3 AND #4

AMED

Aysegul Dirik
a.dirik@qmul.ac.uk

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3 exp CAREGIVER/ OR caregiver* OR carer* OR "social network*" OR famil*
4 **AND**
5 PSYCHIATRY AND PSYCHOLOGY/ OR MENTAL DISORDERS/ OR exp
6 PSYCHOTIC DISORDERS/ OR exp SCHIZOPHRENIA/ OR BIPOLAR
7 DISORDER/ OR (severe* AND mental* AND ill*) OR (serious* AND mental* AND
8 ill*) OR "service user*" OR (consumer AND mental)
9 **AND**
10 exp PATIENT CARE PLANNING/ OR exp PATIENT CARE MANAGEMENT/ OR
11 exp METHODS/ OR exp PATIENT ASSESSMENT/ OR exp PATIENT
12 PARTICIPATION/ OR THERAPY/ OR exp PSYCHOTHERAPY/ OR exp FAMILY
13 THERAPY/ OR program* OR intervention* OR invol*
14 **AND**
15 exp MENTAL HEALTH SERVICES/ OR Crisis OR acute* OR exp INPATIENTS/
16 OR inpatient* OR hospital*

18 CINAHL

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21 ((severe* AND mental* AND ill*) OR (serious* AND mental* AND ill*) OR "service
22 user*" OR (consumer AND mental)).ti,ab
23 **OR**
24 MENTAL DISORDERS/ OR PSYCHOTIC DISORDERS/ OR exp
25 SCHIZOPHRENIA/ OR BIPOLAR DISORDER/
26 **AND**
27 exp *HOSPITALS, PSYCHIATRIC/ OR EXP INPATIENTS/
28 OR (inpatient* OR Crisis OR acute*).ti,ab
29 **AND**
30 PATIENT CARE PLANNING/ OR PSYCHOTHERAPY/ OR FAMILY THERAPY/
31 OR (program* OR intervention* OR invol*).ti,ab
32 **AND**
33 (caregiver* OR carer* OR "social network*" OR famil*).ti,ab
34 OR exp CAREGIVERS/
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36 BNI

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38 exp CAREGIVER/ OR caregiver* OR carer* OR "social network*" OR famil*
39 **AND**
40 PSYCHIATRY AND PSYCHOLOGY/ OR MENTAL DISORDERS/ OR exp
41 PSYCHOTIC DISORDERS/ OR exp SCHIZOPHRENIA/ OR BIPOLAR
42 DISORDER/ OR (severe* AND mental* AND ill*) OR (serious* AND mental* AND
43 ill*) OR "service user*" OR (consumer AND mental)
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BMJ Open

Why Involve Families in Acute Mental Health Care? A Collaborative Conceptual Review

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SCHOLARONE™
Manuscripts

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3 **Why Involve Families in Acute Mental Health Care? A Collaborative Conceptual**
4 **Review**

5
6 Aysegul Dirik¹, Sima Sandhu¹, Domenico Giacco^{1,2}, Katherine Barrett³, Gerry Bennison³, Sue
7 Collinson³, Stefan Priebe¹.
8
9

10 ¹ Unit for Social & Community Psychiatry, (WHO Collaborating Centre for Mental Health
11 Services Development), Queen Mary University of London, United Kingdom

12 ² East London NHS Foundation Trust, United Kingdom

13 ³ Service User/Carer Researcher, supported to participate at ¹ (Queen Mary University of
14 London)
15

16 **Corresponding author:**

17
18 Aysegul Dirik
19 a.dirik@qmul.ac.uk
20 +44 (0)20 7540 4380 ext.2330
21

22 Unit for Social & Community Psychiatry, (WHO Collaborating Centre for Mental Health
23 Services Development), Queen Mary University of London, United Kingdom.
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ABSTRACT

Objectives: Family involvement is strongly recommended in clinical guidelines but suffers from poor implementation. To explore this topic at a conceptual level, a multidisciplinary review team including academics, clinicians and individuals with lived experience undertook a review to explore the theoretical background of family involvement models in acute mental health treatment and how this relates to their delivery.

Design: A conceptual review was undertaken, including a systematic search and narrative synthesis. Included family models were mapped onto the most commonly referenced underlying theories: the diathesis-stress model, systems theories and postmodern theories of mental health. Common components of the models were summarised and compared. Lastly, a thematic analysis was undertaken to explore the role of patients and families in the delivery of the approaches.

Setting: General adult acute mental health treatment.

Results: Six distinct family involvement models were identified: Calgary Family Assessment and Intervention Models, ERIC (Equipe Rapide d'Intervention de Crise, Family Psychoeducation Models, Family Systems Approach (SYMPA), Open Dialogue and the Somerset Model. Findings indicated that despite wide variation in the theoretical models underlying family involvement models, there were many commonalities in their components, such as a focus on communication, language use and joint-decision making. Thematic analysis of the role of patients and families identified several issues for implementation. This included potential harms that could emerge during delivery of the models, such as imposing linear "patient-carer" relationships and the risk of perceived coercion.

Conclusions: We conclude that future staff training may benefit from discussing the chosen family involvement model within the context of other theories of mental health. This may help to clarify the underlying purpose of family involvement and address the diverse needs and world views of patients, families and professionals in acute settings.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- We included distinct family involvement models used internationally in acute mental health treatment.
- We explored the role of underlying theories and potential risks of harm, both of which may impact implementation.
- Our multidisciplinary team included the active contribution of people with lived experience of acute mental health treatment as well as clinicians and academics.
- Broadly mapping across models means we did not include an exhaustive list of every single variation of family involvement in acute treatment.
- The identified models were originally developed in various Western mental health settings, which might not reflect the theoretical frameworks of non-Western settings.

BACKGROUND

Practically all mental health policies and guidelines suggest some form of family, friend or carer involvement in patients' mental health care (hereon abbreviated to "family involvement"). The potential benefits of this for patients are well documented, including relapse prevention and reduced hospital stays.[1,2] Despite growing consensus in policy toward family-inclusive services, in reality, audits consistently highlight poor implementation rates.[3] This problem is well documented: over decades of research, frustrations have been expressed about the difficulties of implementing family involvement into routine psychiatric care.[4,5]

To complicate matters, the reason for conducting family involvement in the first place cannot be traced to a single school of thought or point in time. Socio-political events, such as the deinstitutionalisation of mental health services and early theories of mental illness have meant that families often felt both blamed for mental health problems as well as being given the responsibility of providing support. Family advocacy groups have pushed for policy changes towards recognising the support that families provide, and the burden that can be associated with this.[6] Alongside this, multiple family involvement models have emerged based on divergent theories of the nature of mental health problems.

The use of family involvement models can vary highly between services.[7,8] Evidence is emerging of a lack of shared understanding of what constitutes appropriate family involvement and how to best incorporate it into services [9]. Such discord is problematic, as it can impact staff attitudes and the general organisational culture toward family work.[10] This, in turn, has implications for resource allocation and intervention delivery, particularly if there is disagreement about the aim or value of conducting it.[11,12]

A recent review by members of our team identified multiple barriers to the implementation of family involvement at the individual, team and organisational level.[13] These barriers were common across intervention models and international settings. A particularly challenging setting is acute treatment, which typically involves admission to hospital for inpatient treatment or a crisis intervention in the community. Clinician reports indicate numerous difficulties in implementing family involvement in these contexts, which are often characterised by a strong focus on risk reduction and crisis management.[14]

Revisiting the concepts underlying family work seems timely as it may bring us a step closer to understanding how to implement it in a way that is in keeping with the values of mental health organisations, users of their services and families. This review seeks to explore the diversity across different family involvement models and to consider how their underlying theoretical backgrounds might impact on how they are delivered and received today. We investigated the following questions:

- (1) Which family involvement models are used in general adult acute mental health settings?
- (2) What is the theory or rationale underlying family involvement models?
- (3) What are the components of the models?
- (4) What is the role of patients and family in the delivery of the models?

METHOD

For this review, we did not aim to produce an exhaustive list of every existing family involvement model. Instead, we set out to find distinct approaches that represented the

1
2
3 diversity of the models that are used today. A conceptual review,[15] which enables the
4 exploration of the breadth of concepts in a given area was considered the most appropriate
5 methodology to answer these research questions.[16-19] This review was pre-registered on
6 PROSPERO (CRD42016032749).
7

8 **Search Strategy and Selection Criteria**

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10 A wide search strategy was employed, including a systematic search of electronic databases
11 (Embase, MEDLINE, PsycINFO, BNI, CINAHL and AMED) for descriptors of “family/carers”
12 “mental health” “model/approach” and “setting” and hand searches (see appendix one). AD
13 conducted the searches in consultation with SS and experts in the field. As described below,
14 the searches and analyses were iterative and the chosen key models were finalised during
15 the first stage of analysis.
16

17 We included (1) key texts containing an original description of a family involvement model
18 that (2) referred to the management of an acute mental health situation or the treatment of
19 “severe mental illness” that could be started during the acute phase (3) with a clear
20 description of how families are involved in the patient’s treatment and (4) the primary focus
21 was general adult mental health (ages 18 - 65).
22

23 Papers were excluded if (1) the word “carer” was being used to refer to paid staff members,
24 (2) the primary focus was on specialist services, (3) they were a description of a family
25 therapy model rather than a programme designed for family involvement in acute mental
26 health treatment or (4) it was not possible to obtain an English-language description,
27 although non-English texts were translated whenever possible.
28

29 **Data Analysis**

30

31 A multidisciplinary review team was formed to minimise biases in the searches and
32 analyses.[15] This composed of the lead researcher (AD, a doctoral researcher), a research
33 psychologist (SS), two clinical/academic psychiatrists (DG and SP), three individuals with
34 lived experience of acute mental health treatment, either as patients or as family members
35 (KB, GB and SC) and a clinical nurse manager, who also has research experience (PM).
36 The review team worked most closely on steps two and three below.
37

38 A narrative synthesis was conducted to reach a thorough conceptual understanding of family
39 involvement models.[20] The steps described below were highly iterative:
40

41 1. To develop a preliminary synthesis, found texts were clustered into categories of family
42 involvement models. The clustered groups were expanded and collapsed until the family
43 involvement models were broadly similar within each group and sufficiently different from the
44 other groups. Then, the key texts were identified within each group by reference screening,
45 citation checking and snowballing to find original descriptions of the approach. The final
46 inclusion decision was made after discussions with colleagues and experts in the field.
47

48 Alongside this, the theoretical references of the models were identified by extracting the
49 change processes and reasons for intervention development described in the texts, as well
50 as reference screening, reading widely around the subject area and consulting experts. The
51 chosen family involvement models were mapped on to the identified theories.
52

53 2. Components of the included studies were identified by extracting authors’ descriptions of
54 how the model is carried out and clustering the text into similar methods. Similarities and
55 differences were then compared across the models.
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3. We explored the role of patients and carers within and between the models using thematic analysis.[21] A selection of family involvement models were examined in depth, ensuring there was representation across the identified theoretical references. Analysis of the emerging key themes was conducted iteratively after multiple reflective discussions.

4. As well as utilising our own multidisciplinary review teams, several measures were taken to ensure robustness of the synthesis. This included numerous consultations with a wider team of around 30 researchers, an expert in Family Intervention, two service user research groups (SUGAR, the Service User and carer Group Advising on Research; and SURF, the North London Service User Research Forum), and a Social Psychiatry expert academics meeting. The ROBIS (Risk Of Bias In Systematic reviews) tool was used to guide our methodology, although quality assessment of the included studies themselves was not considered appropriate for this review of concepts.[22]

RESULTS

The analysis was built up at each stage from (1) identifying distinct models (2) mapping the models to their theoretical references (3) comparing the model components and (4) exploring the role of patients and carers in the delivery of the approaches.

1. Key models

We identified six distinct family involvement models from sixteen key sources (table 1). This included four key family psychoeducation models, which were clustered due to the similarity of their underlying approach. The PRISMA flow diagram (figure 1) depicts our selection process.[23]

As will be described, some of the models (e.g. family psychoeducation) were originally developed for the treatment of schizophrenia or psychosis and then adapted to be utilised more widely whereas others were less focused on a particular service context or diagnostic category.

[Figure 1: Study selection]

Model	Country	Description
<i>Calgary Family Assessment and Intervention Models</i> [24]	Canada	Guidelines for family nursing practice and assessment that draw upon systems, communication, and change theory. In acute care, interventions may target cognitive, affective and behavioural domains of family functioning to invoke change. Staff are trained to use systemic tools such as genograms for the assessment of social relationships.
<i>ERIC (Equipe Rapide d'Intervention de Crise)</i> [25]	France	Nurses, doctors and psychologists work together as a large multidisciplinary team in a mobile service. Brief psychotherapy is provided, usually in the patient's home, with the aim of "enveloping" (containing) the crisis. There is strong emphasis on the role of communication and the competence of the family unit to deal with future crises.

<i>Family Psychoeducation Models</i> [26-31]	UK, USA	The most widely used model globally, developed from research into the role of family communication in relapse. Specialist teams provide a package of support including at least (1) an educational component about the patient's diagnosis and the recommended treatment; (2) problem solving and/or communication training to simplify communication for the patient and (3) emotional support for the family.
<i>Family Systems Approach (SYMPA)</i> [32-34]	Germany	All staff across disciplines are trained to assess and treat patients within a systemic framework. This includes changing language use to less medicalised terms. Staff are also trained as "negotiators" between the patient and the organisation about matters such as medication and compulsory measures.
<i>Open Dialogue</i> [35-37]	Finland	A multidisciplinary mobile crisis team attend the patient's home within a short time from referral. Meetings including the patient's wider social network take place daily, and continue until a "joint understanding" is reached of the patient's distress. The process of listening and responding is considered central in reducing the patient's distressed state.
Somerset Model[38,39]	UK	Service-wide approach, developed to address policy and advocacy-led calls for more family-inclusive services. All families are offered an initial needs assessment and information about the service, and may be referred to more intensive provision.

Table 1: Family involvement models in acute mental health care

2. Theory mapping

We then explored how the models relate to their most commonly cited theoretical influences, which included systems theory, the diathesis-stress model and postmodern theories. There were some overlaps in the theoretical references underpinning the models, as illustrated in figure 2.

[Figure 2 : The placement of family involvement models within the diathesis-stress, systems and postmodern theories.]

Systems Theories

Systems theories (e.g. General Systems Theory and Cybernetics)[40-42] are commonly used frameworks for broadly understanding how all systems function and the importance of interactions in those systems. In psychiatry, a major application of these theories has been systemic family therapy.[43-45] Here, the broad principles posit that there is an issue within the family system and that one person within this becomes the designated "patient" presented to services. The professional's role is to work with the whole family to influence the processes that contribute to the patient's mental state.

A minority of the examined models offer traditional systemic family therapy as a supplementary, intensive service for particular families.[32,33,35] However, the general

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3 influence of systems theories is substantial across the models. Historically, whilst some
4 models were developed in part as a reaction to the perceived “blaming” attitude of systemic
5 family therapy,[26,28,29] others used systemic principles as a guideline to set-up family-
6 inclusive services.[25,32-34,38,39] Notably, the majority of models utilise systemic
7 techniques in their everyday practice, such as constructing genograms (social network
8 diagrams) to understand the patient’s social environment[24,32,38,39] and using therapeutic
9 techniques such as circular questioning.[28]

11 *The Diathesis-Stress Theory*

12
13 The diathesis-stress model posits that people with schizophrenia have an underlying
14 physical vulnerability to developing symptoms, the risk of which only manifests if the person
15 experiences excessive environmental stress.[46] Research into potential environmental
16 stressors highlighted several concepts of harmful (or helpful) communication patterns within
17 families.[47]

18
19 Based on this theory, multiple family involvement models were developed to address the
20 underlying biological causes of schizophrenia by using medication as well as providing
21 support and “psychoeducation” to families to teach them the diathesis-stress model and
22 reduce stressful communication that could exacerbate symptoms. [26-31]

23
24 One commonly accepted theory of communication is “Expressed Emotion” (“EE”), which
25 suggests that levels of *hostility*, *criticism*, *overinvolvement*, and *warmth* can affect a person’s
26 likelihood of relapse ”).[47,48] While some models intervened directly in EE communication
27 (e.g. [27-28]), others focused more on developing general communication skills within the
28 family unit to encourage expression and improve problem-solving [26].

29
30 Later, psychoeducation models were developed to include other mental and physical health
31 conditions [49-52] and alternative modes of delivery, including mobile crisis teams [53] and
32 online interventions, including those focused on family members’ own needs.[54,55] In
33 addition, some services have incorporated other concepts such as recovery and peer
34 support [56].

35
36 Whilst the clearest influence of the diathesis-stress theory is on family psychoeducation
37 models,[26-31] arguably its elements exist in all models that take place within a medical
38 system. For example, almost all of the models routinely recommend medication along with
39 psychological support and social interventions (e.g. [32-34]).

41 *Postmodern Theories*

42
43 Postmodern approaches to mental health are often critical of commonly-accepted narratives
44 of “mental illness”. [57] Influential theories within this sphere include social constructionism
45 and constructivism, which broadly posit that mental health problems only exist in social
46 contexts and so their solutions can only emerge within those contexts.[58-60] There are
47 some overlaps with systemic theories, particularly in terms of the importance of viewing the
48 patient within their social context. An area of difference is less focus on interactions within
49 the “system” and more on the individual perspectives people have on their own problems. As
50 a result, postmodern approaches tend to focus less on particular interventions and more on
51 working with uncertainty during the therapeutic process. Whilst the rise in popularity in the
52 1960s is well documented (e.g. [58,59,61]), these viewpoints were not translated to widely
53 used family involvement models, and largely fell out of favour for more medically focused
54 approaches. However, some models developed from postmodern and systemic ideas, often
55 as a reaction to more medical theories.[24,32-37]

Whilst pure postmodernism rejects biological explanations, these models took a more integrated approach, incorporating postmodern theories and practices (e.g. [62-64]) into existing medical systems. Common features included strong emphasis on the wider social context [35-37] and prominence given to individual narratives and explanations [24,35,36] rather than emphasising diagnoses or highly structured treatment models, which could be viewed as imposing “absolute truths” or world views.

3. Synthesis of the components of the approaches

Considering the rich and divergent theoretical background of family involvement models, we examined how these theories related to the components of the models. The section below refers to original descriptions of key family involvement models. In current practice, models have been adapted in countless ways to include different concepts. This includes variation to the methods of service delivery and the inclusion (or exclusion) of particular therapeutic components. However, the most common components across the original descriptions are summarised in table 2 and the following section.

	Communication / Language Use	Joint Decision-Making	Support For The Family	Wider Social Network	Medication Use	Specialist Teams/Staff	Whole Systems Approach
Calgary Family Assessment and Intervention Model [24]	√√	√√	√√	√	√	–	√√
ERIC (Equipe Rapide d'Intervention de Crise) [25]	√√	√	√√	√	√	–	√√
Family Psychoeducation Models [26-31]	√√	√	√√	–	√√	√√	–
Family Systems Approach (SYMPA) [32-34]	√√	√√	√	√	√	–	√√
Open Dialogue [35-37]	√√	√√	√	√√	√	–	√√
Somerset Service Model [38,39]	√	√	√√	√	√	–	√√

Table 2: Common components of family involvement models

(key: √/Strongly emphasised in model; ✓/Present in the model, not a key feature; – Relatively less or no emphasis)

Communication/Language Use

Communication and language use were strongly emphasised across all models. Models adhering to the diathesis-stress theory intervened in EE or other aspects of communication as a tool in relapse prevention.[47,48] In Open Dialogue and ERIC, whilst the theoretical basis was very different, the dialogue between and within participants was theorised as the main driver of change.[25,35-37] Systemic approaches such as the Calgary model trained staff in communication to improve families' service experience [24] whilst in SYMPA staff were trained to avoid diagnostic labels, as they could disempower patients and encourage a "psychiatric career" identity.[32,33]

Joint Decision-Making and the Role of Experts

All the models emphasised the need to make decisions jointly, although the emphasis on experts differed. Models based on the diathesis-stress theory, which are more medical in nature, emphasised the importance of experts who provide "information, advice and guidance" [28]. However, this approach existed in other models, but was not acknowledged as openly. Other models "incompatible" with "the illness concept inherent in the idea of vulnerability and the strong focus on compliance with psychopharmacological treatments" (p.377, [33]) still described how clinicians needed to "negotiate" various aspects of the treatment with the patient and their family.[32-34] Postmodern-influenced models minimised professionals' role in treatment decisions, and made all clinical decisions jointly with the patient and their wider social network. This often meant that the professionals had to "tolerate uncertainty" in the treatment process.[35-37]

Support for the Family Themselves

Some models were developed directly in response to families' stated needs for support and involvement.[27,28,38,39] This could for example prevent the build-up of problems which could manifest as poor communication.[27] More systemic or postmodern influenced models were less focused on family support, and rather saw the involvement of the patient's wider social network as a necessary tool in understanding their social context.[32-34]

Wider Social Network Involvement

The involved "family" differed across the models. Psychoeducation models generally focused on the people the patient lives with (and therefore interacts with the most), meaning it was largely aimed towards parents and partners. [26-31] This was sometimes a deliberate decision based on previous lack of utility when involving extended relatives and friends.[29] Whilst some systemic models also referred to the family in this context [25] others used the term "family" more widely to refer to any members of the patient's "problem determined-system".[34] Open Dialogue, which focuses heavily on interactions within the wider social network placed importance on all its members, including friends, family, neighbours and colleagues.[35-37]

Medication Use

Medication use featured in all models. Approaches that derive more from the diathesis-stress model considered medication to be an important component and the family were sometimes seen as a core resource to help with maintaining adherence.[26,29-31] Whilst the SYMPA model favoured a systemic understanding of the patient's situation, the importance of "negotiation" with the patient regarding medication was emphasised.[32-34] Other systemic and postmodern-influenced models placed less emphasis on its use in the examined texts.[24,25] The greatest variation was in Open Dialogue, as patients were not given medication at the outset. If their condition did not improve, they were offered a low dose, with the aim to taper or discontinue its use over time.[35-37]

System organisation

Finally, a major area of difference was the way the service was organised to deliver family involvement. Models based on the diathesis-stress theory usually required a small group of staff members to be trained as family involvement specialists who could manage the complexities of patient-family work.[26-31] Conversely, systemic models required whole teams to be trained in the principles of family involvement.[24,32-39] Whilst specialist family training was still required, this was applied across the service and was not solely the responsibility of a smaller team.

4. The role of patients and families

For the final research question, a thematic analysis[21] was conducted on the descriptions of the role of patients and families in the delivery of the models (summarised in table 3). The process was highly iterative and included multiple discussions with patients, family members and professionals. This analysis has also been supplemented by existing literature on this topic to reflect wider developments.

Theme	Subthemes
1. Families Are a Resource	
2. Linear Roles and Relationships	2.1. <i>There is a "patient" and a "carer"</i> 2.2. <i>Families want to help</i> 2.3. <i>Family involvement is always beneficial</i>
3. Risk of Identity Loss	
4. Implementation vs. Choice	

Table 3. Themes and subthemes relating to the role of patients and families in family involvement models

1. Families Are a Resource

Families were conceptualised as a resource in a number of ways. They were often seen as "*potentially competent partners*" ([65] cf. [35]) in the stabilisation phase of the patient and in adherence to clinical procedures.[25-27,29,31] They were also perceived as a source of information about the patient's situation - whether directly or by observation.[26,32,33]

However, it was unclear whether family members were given the opportunity to refuse involvement whilst acknowledging the potential feelings of guilt that can emerge from this. Success of a model often seemed to depend on the willingness of the family to accept their "helpful" or "carer" role and to engage with the techniques led by the professionals. Often, there were descriptions of how to engage unwilling family members).[26,31,35,36] This was addressed in some models by emphasis on tools for family members to consider their own needs [e.g. [26, 38-39].

2. Linear Roles and Relationships

2.1. *There is a "patient" and a "carer"*: The relationship between the family and the individual accessing services was presented linearly, unless it was referring to co-dependency.[28] Even in systemic approaches that had circular causation as a theoretical reference, there was a clear, unidirectional "carer" and "patient" role. [24,25,32-34] The possibility of reciprocal support or a more egalitarian or independent relationship was not explicitly described in the examined models. This was also highlighted as an issue by individuals who hold mutual "patient" and "carer" roles during the analysis and consultation process. The role of reciprocity in caregiving in mental health is however explored in other research literature [66] and may hold a more prominent role in everyday clinical practice.

2.2. *Families want to help*: Related to this, it was generally assumed that families either want involvement in the patient's treatment, or do not want it because they have been let down by professionals in the past.[26,38,39] This in accordance with wider literature in the area, which highlights difficulties families experience when requesting involvement and information in clinical settings [67,68]. An alternative view that emerged from family members during the analysis process was that families might care for a relative but not want to feel responsible for their treatment. This was not explored in the examined texts but wider literature suggests a range of tools to support family members, which may help to overcome such difficulties in practice [69].

2.3. *Family involvement is always beneficial*: Moreover, whilst it was acknowledged that not everyone has supportive family members and that some relationships might be complicated, it was generally assumed that the involvement of family would be beneficial.[31,35,36] This idea is widely supported in wider literature (e.g.[1,2]). However, as described next, the analysis process also indicated potential harms of involvement, which were often not explored in the examined texts. These ideas largely emerged from discussions of the personal lived experiences of patients and family members during the analysis process.

3. Risk of Identity Loss

Considering the inherent vulnerability of being an individual in acute care, the positive and negative implications of involving others seemed greater. Clearly, family and friends could be a source of comfort and support in a difficult setting. However, sharing one's private information in a setting where they are the "patient in need" could also risk altering their roles and relationships after they left acute treatment. In approaches with a wider social network approach, this potentially carried a higher risk. For example, colleagues may be invited to treatment meetings.[35-37] It seemed important to consider whether the patient in crisis could make a fully informed decision about the consequences of this and the possible impact this could have when they return to work.

Moreover, a general lack of accounts from patients themselves across the models meant that the "patient" could sometimes be described as a passive recipient of the interventions. Examples of individuals taking a more active role included psychoeducation that enlisted patients to share their own accounts[26] and patients being a core part of joint decision-making.[35-37]

4. Implementation vs. Choice

Considering these points, we contemplated the role of patient choice in family involvement and how the structure of service organisation might affect this. If a whole service is set up to operate on the principles that family involvement is fundamental to psychiatric treatment, this makes it more likely to be implemented, as all staff are fully trained in facilitating it.[24,32-39] However, depending on the delivery of the approach, this also has greater potential to

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3 weaken the patient's voice in the matter, making them feel pressured to involve others in a
4 process they might have preferred to remain private. Conversely, if there are only specialist
5 family involvement teams within a larger system, this can soon become an underused
6 "niche" service. In this case, the specialist team must rely on external factors such as
7 managers and other colleagues seeing value in their approach, providing resources and
8 collaborating to identify and refer "suitable" families to the service, all of which can result in
9 lower implementation.[13,26-31] Overall, whilst there may be no ideal approach to service
10 organisation, the way "choice" is presented appeared to be an important factor.
11

12 13 DISCUSSION

14
15 This review broadly identified key family involvement models in acute mental health
16 treatment and considered how their theoretical references are related to their delivery. From
17 this, we considered how patients and families might be impacted. Despite major theoretical
18 differences, we found many similarities in the components of the models, which raised the
19 question: what is the intended aim when involving families and is it important to specify this?
20 Namely, should all models be considered the same or is the theoretical basis an important
21 aspect of delivery? Perhaps, as has been suggested for individual psychotherapy,
22 nonspecific factors (e.g. the therapeutic relationship) determine the usefulness of the chosen
23 model.[70] However, it may be important to place the model within its wider theoretical
24 context to aid staff training and understanding, particularly in light of difficulties with
25 implementation in this field [3]
26

27 For example, there may be a conflict in how staff should conceptualise the "patient" and
28 "family" roles and relationships. MacFarlane highlights how clinicians might struggle to be
29 simultaneously family-positive and inclusive despite being taught that they are at least
30 partially responsible for the patient's problems.[71] Acknowledging these tensions and
31 finding a way to integrate divergent world views may increase the likelihood of offering family
32 involvement more consistently across services.
33

34 It is also important to consider that overall, a significant aspect of implementation is how well
35 a model fits with a service's existing values.[72] Family psychoeducation is most strongly
36 aligned with the existing biopsychosocial medical model, and this might be one reason why it
37 fits more easily into existing services than postmodern or systemic models. The
38 fundamentals of the latter approaches might be harder to train clinicians who have primarily
39 been taught the biopsychosocial model, and to obtain resources through regular funding
40 structures which prioritise medically-focused clinical outcomes.
41

42 In considering implementation, the importance of patient and family experience should also
43 be emphasised. For example, choice emerged as a significant consideration in our review.
44 Too much focus on system-wide implementation could mean more likelihood of some
45 patients feeling coerced into involving others during what is preferred to be a private
46 process. This is of particular importance considering the potential harmful impacts of
47 assuming individuals hold particular roles in their relationship. For example, a mother having
48 a mental health crisis might not wish for her son to be present as a "carer" in her most acute
49 phase, even if he is of adult age. This risks not only taking away her role as a person who
50 holds authority and respect (a "parent") but it might impact on the dynamics of their
51 relationship after the acute episode has subsided. This notion corresponds with Goffman's
52 theories of the risk of identity loss in inpatient settings.[61]
53

54
55 Our review also indicated the potential for family members to feel disempowered by being
56 viewed as a resource for services. This point was recently raised by Meijer and colleagues,
57 who highlight the tension of being imposed the role of "carer" whilst having one's own goals
58 and needs to attend to.[73] Rugkåsa's comprehensive review of elements of coercion in
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1
2
3 caring also makes the point that families may wish to be less involved in the care of their
4 relative but fear the consequences of doing so.[74]
5

6 It is important to note here that a large body of research evidence supports the view that
7 many families wish to have significantly more involvement, particularly in crisis
8 contexts.[75,76] However, this review highlights the challenges of accommodating diverse
9 needs in an already complex service setting. Overall, the offer of family involvement requires
10 a delicate balance on the part of service leaders to support availability whilst maximising
11 patients' and families' decision-making in the process.
12

13 **Strengths and Limitations**

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15 This review has a number of strengths and limitations to consider. To our knowledge this is
16 the first conceptual review that has actively included people with lived experience of mental
17 health services alongside academics and clinicians in the review team. This has allowed for
18 in-depth integrations of personal and professional experiences of family involvement. This
19 has contributed to a deeper understanding of not just the concepts present in each model,
20 but also what is *not* explained. From the latter, potential problems in the delivery of
21 interventions were revealed. Research into patient safety emphasises the benefits of
22 involving people with lived experience in identifying unknown latent harms.[77]
23

24 Although we conducted a systematic search, our findings are by no means an exhaustive list
25 of all existing family involvement models. We avoided this for pragmatic reasons: in practice,
26 the implementation of family involvement models can vary greatly, resulting in an infinite
27 number of ways each component can be delivered. Investigating these infinite nuances will
28 not necessarily lead to a better understanding of the field as a whole. Instead, a broad
29 understanding of the diversity of the models that exist, and their common concepts, signifies
30 the basis of family involvement in most settings.
31

32 Finally, due to the emphasis on published articles and manuals, the majority of literature was
33 based in Europe, the USA and Australasia, or what is often referred to as the "Western"
34 medical system. This common problem can impact how relevant the results are cross-
35 culturally.[78] Moreover, there may be an influence of the local context on the development
36 and delivery of the included models, which might not translate to other settings. For
37 example, rural environments might have more traditional family support structures than
38 urban settings, affecting the nature of the involvement that can take place. However, when
39 screening articles we struck by how globalised family involvement approaches had become,
40 particular the adaptation of family psychoeducation to a number of international contexts.
41 [79-81] How well this approach integrates with existing belief systems is a matter for another
42 enquiry.
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45 **Conclusions**

46
47 Although family involvement models have been developed in the context of diverse
48 theoretical perspectives and socio-political events, there are many commonalities in their
49 components. Despite these commonalities, it must be acknowledged that the models are
50 different in nature and underlying purpose. To enhance staff training and support
51 implementation, there may be value in discussing the fundamentals of why family
52 involvement is conducted, how it might be experienced by patients and families and how this
53 relates to staff members' own perspectives. We therefore encourage further discussion of
54 the differences and similarities between the various models and theories, taking into
55 consideration different ideas about the nature of mental health and the purpose of involving
56 families in these contexts.
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COMPETING INTERESTS

None declared.

DATA SHARING STATEMENT

There are no additional unpublished data to share.

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AUTHORS' CONTRIBUTIONS

AD designed the study, conducted searches and data extraction (in consultation with SS and SP), led on the analysis and prepared the manuscript. All authors contributed to the analysis, critically reviewed the paper and approved the final manuscript. SP and SS provided overall guidance and supervision for the study.

REFERENCES

- 1 Pharoah F, Mari J, Rathbone J, *et al*. Family intervention for schizophrenia. *Cochrane Database of Systematic Reviews* 2010;**12**.
- 2 Garety P, Pilling S, Bebbington P, *et al*. Psychological treatments in schizophrenia: I. Meta-analysis of family intervention and cognitive behaviour therapy. *Psychol Med* 2002;**32**:763–82. doi:10.1017/S0033291702005895
- 3 Ince P, Haddock G, Tai S. A systematic review of the implementation of recommended psychological interventions for schizophrenia: Rates, barriers, and improvement strategies. *Psychology and Psychotherapy: Theory, Research and Practice* Published Online First: 5 November 2015. doi:10.1111/papt.12084
- 4 Macfarlane MM. *Family Therapy and Mental Health*. Routledge 2013.
- 5 Mairs H, Bradshaw T. Implementing family intervention following training: what can the matter be? *Journal of Psychiatric and Mental Health Nursing* 2005;**12**:488–94. doi:10.1111/j.1365-2850.2005.00871.x
- 6 Worthington A, Rooney P. The Triangle of Care; Carers included: A guide to best practice in acute mental health care. 2010;:1–32.
- 7 Hofmann SG, Tompson MC. *Treating Chronic and Severe Mental Disorders: A Handbook of Empirically Supported Interventions*. Guilford Press 2002.
- 8 Eisler I. A rose by any other name. *Journal of Family Therapy* 2005.
- 9 Kavanagh DJ. What the Problem May Be With Family Intervention ... and With Dissemination More Generally: A Commentary. *Australian Psychologist* 2016;**51**:69–72. doi:10.1111/ap.12205
- 10 Fadden G, Birchwood M, Lefley H, *et al*. British models for expanding family psychoeducation in routine practice. *Family interventions in mental illness: International perspectives* 2002;:25–42.
- 11 Brooker C, Butterworth C. Working with families caring for a relative with schizophrenia: the evolving role of the community psychiatric nurse. *International Journal of Nursing Studies* 1991;**28**:189–200.
- 12 Brent BK, Giuliano AJ. Psychotic-spectrum illness and family-based treatments: a case-based illustration of the underuse of family interventions. *Harvard Review of Psychiatry* 2007;**15**:161–8.
- 13 Eassom E, Giacco D, Dirik A, *et al*. Implementing family involvement in the treatment of patients with psychosis: a systematic review of facilitating and hindering factors. *BMJ Open* 2014;**4**:e006108–8. doi:10.1136/bmjopen-2014-006108
- 14 Fadden G. Overcoming barriers to staff offering family interventions in the NHS. In: *A Casebook of Family Interventions for Psychosis*. John Wiley and Sons 2009. 309.
- 15 Lilford RJ, Richardson A, Stevens A, *et al*. Issues in methodological research: perspectives from researchers and commissioners. *Health Technology Assessment* 2001;**5**. doi:10.3310/hta5080

- 1
2
3 16 Priebe S, Dimic S, Wildgrube C, *et al.* Good communication in psychiatry – a
4 conceptual review. *European Psychiatry* 2011;**26**:403–7.
5 doi:10.1016/j.eurpsy.2010.07.010
6
7 17 Chow WS, Priebe S. Understanding psychiatric institutionalization: a conceptual review.
8 *BMC Psychiatry* 2013;**13**:1–1. doi:10.1186/1471-244X-13-169
9
10 18 Priebe S, Omer S, Giacco D, *et al.* Resource-oriented therapeutic models in psychiatry:
11 conceptual review. *The British Journal of Psychiatry* 2014;**204**:256–61.
12 doi:10.1192/bjp.bp.113.135038
13
14 19 Leamy M, Bird V, Le Boutillier C, *et al.* Conceptual framework for personal recovery in
15 mental health: systematic review and narrative synthesis. *The British Journal of*
16 *Psychiatry* 2011;**199**:445–52. doi:10.1192/bjp.bp.110.083733
17
18 20 Popay J, Roberts H, Sowden A, *et al.* Guidance on the conduct of narrative synthesis in
19 systematic reviews. 2006.
20
21 21 Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in*
22 *Psychology* 2006;**3**:77–101. doi:10.1191/1478088706qp063oa
23
24 22 Whiting P, Savović J, Higgins JPT, *et al.* ROBIS: A new tool to assess risk of bias in
25 systematic reviews was developed. *Journal of Clinical Epidemiology* 2016;**69**:225–34.
26 doi:10.1016/j.jclinepi.2015.06.005
27
28 23 Moher D, Liberati A, Tetzlaff J, *et al.* Preferred Reporting Items for Systematic Reviews
29 and Meta-Analyses: The PRISMA Statement. *Ann Intern Med* 2009;**151**:264–9.
30 doi:10.7326/0003-4819-151-4-200908180-00135
31
32 24 Wright LM, Leahey M. *Nurses and Families: a guide to family assessment and*
33 *intervention (6th ed)*. F A Davis Philadelphia. 2013.
34
35 25 Zeltner L, Ampelas J-F, Mallat V, *et al.* Prise en charge de crise et enveloppe
36 langagière. *Thérapie Familiale* 2002;**Vol. 23**:357–66. doi:10.3917/TF.024.0357
37
38 26 Falloon IRH. *Family care of schizophrenia: a problem-solving approach to the treatment*
39 *of mental illness*. Guilford Press New York.1984.
40
41 27 Leff J, Berkowitz R, Eberlein-Vries R, *et al.* A controlled trial of social intervention in the
42 families of schizophrenic patients. *The British Journal of Psychiatry* 1982;**141**:121–34.
43 doi:10.1192/bjp.141.2.121
44
45 28 Kuipers L, Leff J, Lam D. *Family Work for Schizophrenia*. RCPsych Publications 2002.
46
47 29 Anderson CM, Reiss DJ, Hogarty GE. *Schizophrenia and the Family*. Guilford Press
48 1986.
49
50 30 Hogarty GE, Anderson CM, Reiss DJ, *et al.* Family Psychoeducation, Social Skills
51 Training, and Maintenance Chemotherapy in the Aftercare Treatment of Schizophrenia:
52 I. One-Year Effects of a Controlled Study on Relapse and Expressed Emotion. *Archives*
53 *of General Psychiatry* 1986;**43**:633–42. doi:10.1001/archpsyc.1986.01800070019003
54
55 31 Barrowclough C, Tarrrier N. *Families of Schizophrenic Patients*. Nelson Thornes 1992.
56
57 32 Schweitzer J, Ginap C, Twardowski Von J. Training psychiatric teams to do family
58 systems acute psychiatry. *Journal of Family Therapy* 2007;**29**:3–20. doi:10.1111/j.1467-
59
60

- 6427.2007.00366.x
- 33 Schweitzer J, Zwack J, Nicolai E, *et al.* Family systems psychiatry: principles, good practice guidelines, clinical examples, and challenges. *American Journal of Orthopsychiatry* 2007;**77**:377–85. doi:10.1037/0002-9432.77.3.377
- 34 Haun MW, Kordy H, Ochs M, *et al.* Family systems psychiatry in an acute in-patient setting: the implementation and sustainability 5 years after its introduction. *Journal of Family Therapy* 2013;**35**:159–75. doi:10.1111/j.1467-6427.2012.00586.x
- 35 Seikkula J, Alakare B, Aaltonen J. Open dialogue in psychosis I: An introduction and case illustration. *Journal of Constructivist ...* 2001;**14**:247–65. doi:10.1080/10720530125965
- 36 Seikkula J, Alakare B, Aaltonen J. Open dialogue in psychosis II: A comparison of good and poor outcome cases. *Journal of Constructivist ...* 2001;**14**:267–84. doi:10.1080/10720530126129
- 37 Seikkula J, Aaltonen J, Alakare B, *et al.* Five-year experience of first-episode nonaffective psychosis in open-dialogue approach: Treatment principles, follow-up outcomes, and two case studies. *Psychotherapy Research* 2006;**16**:214–28. doi:10.1080/10503300500268490
- 38 Stanbridge R, Burbach F. Developing family-inclusive mainstream mental health services. *Journal of Family Therapy* 2007;**29**. doi:10.1111/j.1467-6427.2007.00367.x
- 39 Stanbridge R, Burbach F. Establishing family inclusive acute inpatient mental health services: a staff training programme in Somerset. *Journal of Family Therapy* 2009;**31**:233–49. doi:10.1111/j.1467-6427.2009.00467.x
- 40 The history and status of general systems theory. *Academy of Management Journal* 1972;**15**:407–26.
- 41 Wiener N. *Cybernetics Or Control and Communication in the Animal and the Machine*. MIT Press 1961. doi:10.2307/41885113
- 42 Ashby WR. *An Introduction to Cybernetics*. London: : Chapman & Hall 1956.
- 43 Selvini-Palazzoli M, Boscolo L, Cecchin G, *et al.* *Paradox and counterparadox: A new model in the therapy of the family in schizophrenic transaction (tsl., EV Burt)*. New York: Jason Aronson 1978.
- 44 Haley J, Erickson MH. *Uncommon therapy*. Norton New York 1973.
- 45 Minuchin S. *Families and therapy*. Structural family therapy in theory and practice (Swe.) ... 1974.
- 46 Zubin J, Spring B. Vulnerability: A new view of schizophrenia. *Journal of Abnormal Psychology* 1977;**86**:103–26. doi:10.1037/0021-843X.86.2.103
- 47 Brown GW, Birley JL, Wing JK. Influence of family life on the course of schizophrenic disorders: A replication. *The British Journal of Psychiatry* 1972;**121**:241–58. doi:10.1192/bjp.121.3.241
- 48 Vaughn CE, Leff JP. The influence of family and social factors on the course of

- 1
2
3 psychiatric illness. A comparison of schizophrenic and depressed neurotic patients. *The*
4 *British Journal of Psychiatry* 1976;**129**:125–37. doi:10.1192/bjp.129.2.125
- 5
6 49 Miklowitz DJ. *Bipolar disorder: A family-focused treatment approach*. 2010.
- 7
8 50 Hutchison SD, Steginga SK, Dunn J. The tiered model of psychosocial intervention in
9 cancer: a community based approach. *Psycho-Oncology* 2006;**15**:541–6.
10 doi:10.1002/pon.973
- 11
12 51 Alloway SC, Toth EL. Effectiveness of a group psychoeducation program for the
13 treatment of subclinical disordered eating in women with type 1 diabetes. *Canadian*
14 *Journal of ...* 2001.
- 15
16 52 Garner DM, Rockert W, Olmsted MP. Psychoeducational principles in the treatment of
17 bulimia and anorexia nervosa. ... *for anorexia nervosa ...* 1985.
- 18
19 53 McFarlane WR, Stastny P, Deakins S. Family-aided assertive community treatment: A
20 comprehensive rehabilitation and intensive case management approach for persons
21 with schizophrenic disorders. *New directions for mental health services* 1992;**1992**:43–
22 54.
- 23
24 54 Sin J, Henderson C, Pinfold V, *et al*. The E Sibling Project—exploratory randomised
25 controlled trial of an online multi-component psychoeducational intervention for siblings
26 of individuals with first episode psychosis. *BMC Psychiatry* 2013;**13**:123.
- 27
28 55 Alvarez-Jimenez M, Alcazar-Corcoles MA, González-Blanch C, *et al*. Online, social
29 media and mobile technologies for psychosis treatment: A systematic review on novel
30 user-led interventions. *Schizophrenia Research* 2014;**156**:96–106.
31 doi:10.1016/j.schres.2014.03.021
- 32
33 56 Heumann K, Janßen L, Ruppelt F. **A pilot study of peer support for relatives of**
34 **individuals with severe mental health problems: Effects on burden and quality of**
35 **life.** *Zeitschrift für Psychiatrie, Psychologie und Psychotherapie* 2016;**64**:45–53.
36 doi:10.1024/1661-4747/a000259
- 37
38 57 Seikkula J, Aaltonen J, Alakare B, *et al*. *Treating psychosis by means of open dialogue.*
39 *The reflective team in action: ...* 1995.
- 40
41 58 Laing RD. *The divided self: A study of sanity and madness*. London: Tavistock 1960.
- 42
43 59 Foucault M. *Maladie Mentale Et Psychologie*. Univ of California Press 1966.
- 44
45 60 Gergen KJ. The social constructionist movement in modern psychology. *American*
46 *Psychologist* 1985;**40**:266–75. doi:10.1037/0003-066X.40.3.266
- 47
48 61 Goffman E. *Asylums*. 1968.
- 49
50 62 Bakhtin MM. *The dialogic imagination: Four essays*. 2010.
- 51
52 63 Bakhtin M, Emerson C. *Problems of Dostoevsky's poetics*. 1993.
- 53
54 64 Moules NJ. Postmodernism and the Sacred: Reclaiming Connection in Our Greater-
55 Than-Human Worlds. *Journal of Marital and Family Therapy* 2000;**26**:229–40.
- 56
57 65 *The Recognition and Management of Early Psychosis*. 1999.
- 58
59
60

- 1
2
3 66 Horwitz AV, Reinhard SC, Howell-White S. Caregiving as Reciprocal Exchange in
4 Families with Seriously Mentally Ill Members. *Journal of Health and Social Behavior*
5 1996;**37**:149–62. doi:10.2307/2137270
6
7 67 Gray B, Robinson C, Seddon D, *et al.* “Confidentiality smokescreens” and carers for
8 people with mental health problems: the perspectives of professionals. *Health Soc Care*
9 *Community* 2008;**16**:378–87. doi:10.1111/j.1365-2524.2007.00748.x
10
11 68 Jankovic J, Yeeles K, Katsakou C, *et al.* Family Caregivers' Experiences of Involuntary
12 Psychiatric Hospital Admissions of Their Relatives – a Qualitative Study. *PLoS ONE*
13 2011;**6**:e25425–7. doi:10.1371/journal.pone.0025425
14
15 69 Yesufu-Udechuku A, Harrison B, Mayo-Wilson E, *et al.* Interventions to improve the
16 experience of caring for people with severe mental illness: systematic review and meta-
17 analysis. *The British Journal of Psychiatry* 2015;**206**:268–74.
18 doi:10.1192/bjp.bp.114.147561
19
20 70 Ahn H-N, Wampold BE. Where oh where are the specific ingredients? A meta-analysis
21 of component studies in counseling and psychotherapy. *Journal of Counseling*
22 *Psychology* 2001;**48**:251–7. doi:10.1037/0022-0167.48.3.251
23
24 71 McFarlane WR. *Families in the treatment of psychotic disorders*. Harvard Mental Health
25 Letter 1995.
26
27 72 Greenhalgh T, Robert G, Bate P, *et al.* *Diffusion of innovations in health service*
28 *organisations: a systematic literature review*. John Wiley & Sons 2008.
29
30 73 Meijer E, Schout G, Abma T. Am I My Brother's Keeper? Moral Dimensions of Informal
31 Caregiving in a Neoliberal Society. *Health Care Analysis* 2016;:1–15.
32 doi:10.1007/s10728-016-0313-7
33
34 74 Rugkåsa J. Family carers and coercion in the community. *Coercion in Community*
35 *Mental Health Care: ...* 2016.
36
37 75 Wilkinson C, McAndrew S. “I’m not an outsider, I’m his mother!” A phenomenological
38 enquiry into carer experiences of exclusion from acute psychiatric settings. *Int J Ment*
39 *Health Nurs* 2008;**17**:392–401. doi:10.1111/j.1447-0349.2008.00574.x
40
41 76 Walkup J. Family involvement in general hospital inpatient care. 1997;:51–64.
42 doi:10.1002/yd.23319977307
43
44 77 Wright J, Lawton R, O’Hara J, *et al.* Improving patient safety through the involvement of
45 patients: development and evaluation of novel interventions to engage patients in
46 preventing patient safety incidents and protecting them against unintended harm.
47 *Programme Grants for Applied Research* 2016;**4**:1–296. doi:10.3310/pgfar04150
48
49 78 Berry JW, Poortinga YH, Breugelmans SM, *et al.* *Cross-Cultural Psychology*.
50 Cambridge University Press 2011.
51
52 79 Eker F, Harkin S. Effectiveness of six-week psychoeducation program on adherence of
53 patients with bipolar affective disorder. *Journal of Affective Disorders* 2012;**138**:409–16.
54 doi:10.1016/j.jad.2012.01.004
55
56 80 Chan SW-C, Yip B, Tso S, *et al.* Evaluation of a psychoeducation program for Chinese
57 clients with schizophrenia and their family caregivers. *Patient Education and*
58
59
60

1
2
3 *Counseling* 2009;**75**:67–76. doi:10.1016/j.pec.2008.08.028
4

- 5 81 Hackethal V, Spiegel S, Lewis-Fernández R, *et al.* Towards a Cultural Adaptation of
6 Family Psychoeducation: Findings from Three Latino Focus Groups. *Community Ment*
7 *Health J* 2013;**49**:587–98. doi:10.1007/s10597-012-9559-1
8
9
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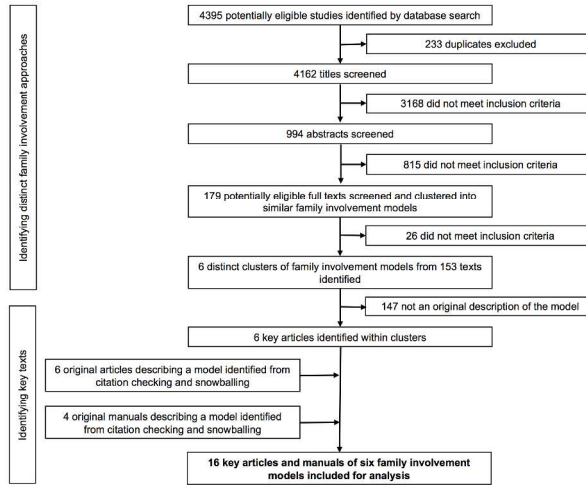


Figure 1: PRISMA flow diagram depicting study selection

297x209mm (300 x 300 DPI)

Review only

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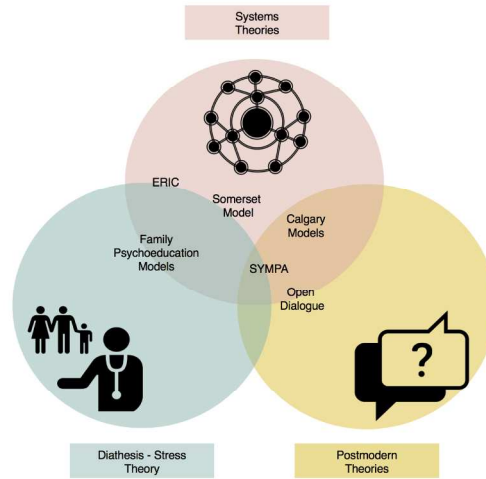


Figure 2: The placement of family involvement models within the diathesis-stress, systems and postmodern theories

297x209mm (300 x 300 DPI)

Review only

Appendix 1: Search Strategy

Embase/MEDLINE

1. 'caregiver'/exp OR 'caregiver' OR carer*:ab,ti OR (social NEXT/2 network*):ab,ti OR famil*:ab,ti
2. 'psychosis'/exp OR 'psychosis' OR 'bipolar disorder'/exp OR 'bipolar disorder' OR 'mental patient'/exp OR 'mental patient' OR (severe* NEXT/2 mental*):ab,ti AND ill*:ab,ti OR ((serious* NEXT/2 mental*):ab,ti AND ill*:ab,ti) OR (service NEXT/1 user*):ab,ti OR (consumer:ab,ti AND mental:ab,ti) OR 'mental disease'/exp OR 'mental disease'
3. 'mental health care'/exp OR 'mental health care' OR 'crisis intervention'/exp OR 'crisis intervention' OR 'involuntary commitment'/exp OR 'involuntary commitment' OR 'inpatient'/exp OR 'inpatient' OR 'psychiatric department'/exp OR 'psychiatric department' OR acute:ab,ti
4. 'medication therapy management'/exp OR 'medication therapy management' OR 'program development'/exp OR 'program development' OR 'patient care planning'/exp OR 'patient care planning' OR 'health services research'/exp OR 'health services research' OR intervention:ab,ti OR involv*:ab,ti OR program*:ab,ti AND ('psychotherapy'/exp OR 'psychotherapy') OR 'psychotherapy'/exp OR 'psychotherapy'
5. #1 AND #2 AND #3 AND #4

PsycINFO

1. DE "Caregivers" OR MM "Social Networks" OR (DE "Family Members" OR DE "Family") OR Carer* OR Famil* OR caregiv*
2. DE "Psychosis" OR DE "Acute Psychosis" OR DE "Affective Psychosis" OR DE "Chronic Psychosis" OR DE "Schizophrenia" OR MM "Bipolar Disorder" OR MM "Cyclothymic Personality" OR MM "Mental Disorders" OR ((Severe* OR serious*) AND Mental* AND Ill*) OR (Service AND User*) OR (Consumer* AND Mental)
3. MM "Involuntary Treatment" OR MM "Psychiatric Hospitalization" OR MM "Psychiatric Hospital Admission" OR MM "Psychiatric Hospital Discharge" OR MM "Psychiatric Hospital Readmission" OR DE "Psychiatric Hospital Admission" OR MM "Psychiatric Units" OR MM "Crisis Intervention" OR acute* OR inpatient
4. DE "Treatment Planning" OR DE "Discharge Planning" OR (DE "Intervention" OR DE "Crisis Intervention" OR DE "Early Intervention" OR DE "Family Intervention" OR DE "Group Intervention") OR (MM "Mental Health Services") OR MM "Program Development" OR involv* OR program* OR interven*
5. #1 AND #2 AND #3 AND #4

AMED

Aysegul Dirik
a.dirik@qmul.ac.uk

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3 exp CAREGIVER/ OR caregiver* OR carer* OR "social network*" OR famil*
4 **AND**
5 PSYCHIATRY AND PSYCHOLOGY/ OR MENTAL DISORDERS/ OR exp
6 PSYCHOTIC DISORDERS/ OR exp SCHIZOPHRENIA/ OR BIPOLAR
7 DISORDER/ OR (severe* AND mental* AND ill*) OR (serious* AND mental* AND
8 ill*) OR "service user*" OR (consumer AND mental)
9 **AND**
10 exp PATIENT CARE PLANNING/ OR exp PATIENT CARE MANAGEMENT/ OR
11 exp METHODS/ OR exp PATIENT ASSESSMENT/ OR exp PATIENT
12 PARTICIPATION/ OR THERAPY/ OR exp PSYCHOTHERAPY/ OR exp FAMILY
13 THERAPY/ OR program* OR intervention* OR invol*
14 **AND**
15 exp MENTAL HEALTH SERVICES/ OR Crisis OR acute* OR exp INPATIENTS/
16 OR inpatient* OR hospital*

18 CINAHL

19
20
21 ((severe* AND mental* AND ill*) OR (serious* AND mental* AND ill*) OR "service
22 user*" OR (consumer AND mental)).ti,ab
23 **OR**
24 MENTAL DISORDERS/ OR PSYCHOTIC DISORDERS/ OR exp
25 SCHIZOPHRENIA/ OR BIPOLAR DISORDER/
26 **AND**
27 exp *HOSPITALS, PSYCHIATRIC/ OR EXP INPATIENTS/
28 OR (inpatient* OR Crisis OR acute*).ti,ab
29 **AND**
30 PATIENT CARE PLANNING/ OR PSYCHOTHERAPY/ OR FAMILY THERAPY/
31 OR (program* OR intervention* OR invol*).ti,ab
32 **AND**
33 (caregiver* OR carer* OR "social network*" OR famil*).ti,ab
34 OR exp CAREGIVERS/
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36 BNI

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38 exp CAREGIVER/ OR caregiver* OR carer* OR "social network*" OR famil*
39 **AND**
40 PSYCHIATRY AND PSYCHOLOGY/ OR MENTAL DISORDERS/ OR exp
41 PSYCHOTIC DISORDERS/ OR exp SCHIZOPHRENIA/ OR BIPOLAR
42 DISORDER/ OR (severe* AND mental* AND ill*) OR (serious* AND mental* AND
43 ill*) OR "service user*" OR (consumer AND mental)
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46 exp METHODS/ OR exp PATIENT ASSESSMENT/ OR exp PATIENT
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48 THERAPY/ OR program* OR intervention* OR invol*
49 **AND**
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51 OR inpatient* OR hospital*
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BMJ Open

Why Involve Families in Acute Mental Health Care? A Collaborative Conceptual Review

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SCHOLARONE™
Manuscripts

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2
3 **Why Involve Families in Acute Mental Health Care? A Collaborative Conceptual**
4 **Review**

5
6 Aysegul Dirik¹, Sima Sandhu¹, Domenico Giacco^{1,2}, Katherine Barrett³, Gerry Bennison³, Sue
7 Collinson³, Stefan Priebe¹.
8

9
10 ¹ Unit for Social & Community Psychiatry, (WHO Collaborating Centre for Mental Health
11 Services Development), Queen Mary University of London, United Kingdom

12 ² East London NHS Foundation Trust, United Kingdom

13 ³ Service User/Carer Researcher, supported to participate at ¹ (Queen Mary University of
14 London)
15

16 **Corresponding author:**

17
18 Aysegul Dirik
19 a.dirik@qmul.ac.uk
20 +44 (0)20 7540 4380 ext.2330
21

22 Unit for Social & Community Psychiatry, (WHO Collaborating Centre for Mental Health
23 Services Development), Queen Mary University of London, United Kingdom.
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ABSTRACT

Objectives: Family involvement is strongly recommended in clinical guidelines but suffers from poor implementation. To explore this topic at a conceptual level, a multidisciplinary review team including academics, clinicians and individuals with lived experience undertook a review to explore the theoretical background of family involvement models in acute mental health treatment and how this relates to their delivery.

Design: A conceptual review was undertaken, including a systematic search and narrative synthesis. Included family models were mapped onto the most commonly referenced underlying theories: the diathesis-stress model, systems theories and postmodern theories of mental health. Common components of the models were summarised and compared. Lastly, a thematic analysis was undertaken to explore the role of patients and families in the delivery of the approaches.

Setting: General adult acute mental health treatment.

Results: Six distinct family involvement models were identified: Calgary Family Assessment and Intervention Models, ERIC (Equipe Rapide d'Intervention de Crise, Family Psychoeducation Models, Family Systems Approach (SYMPA), Open Dialogue and the Somerset Model. Findings indicated that despite wide variation in the theoretical models underlying family involvement models, there were many commonalities in their components, such as a focus on communication, language use and joint-decision making. Thematic analysis of the role of patients and families identified several issues for implementation. This included potential harms that could emerge during delivery of the models, such as imposing linear "patient-carer" relationships and the risk of perceived coercion.

Conclusions: We conclude that future staff training may benefit from discussing the chosen family involvement model within the context of other theories of mental health. This may help to clarify the underlying purpose of family involvement and address the diverse needs and world views of patients, families and professionals in acute settings.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- We included distinct family involvement models used internationally in acute mental health treatment.
- We explored the role of underlying theories and potential risks of harm, both of which may impact implementation.
- Our multidisciplinary team included the active contribution of people with lived experience of acute mental health treatment as well as clinicians and academics.
- Broadly mapping across models means we did not include an exhaustive list of every single variation of family involvement in acute treatment.
- The identified models were originally developed in various Western mental health settings, which might not reflect the theoretical frameworks of non-Western settings.

BACKGROUND

Practically all mental health policies and guidelines suggest some form of family, friend or carer involvement in patients' mental health care (hereon abbreviated to "family involvement"). The potential benefits of this for patients are well documented, including relapse prevention and reduced hospital stays.[1,2] Despite growing consensus in policy toward family-inclusive services, in reality, audits consistently highlight poor implementation rates.[3] This problem is well documented: over decades of research, frustrations have been expressed about the difficulties of implementing family involvement into routine psychiatric care.[4,5]

To complicate matters, the reason for conducting family involvement in the first place cannot be traced to a single school of thought or point in time. Socio-political events, such as the deinstitutionalisation of mental health services and early theories of mental illness have meant that families often felt both blamed for mental health problems as well as being given the responsibility of providing support. Family advocacy groups have pushed for policy changes towards recognising the support that families provide, and the burden that can be associated with this.[6] Alongside this, multiple family involvement models have emerged based on divergent theories of the nature of mental health problems.

The use of family involvement models can vary highly between services.[7,8] Evidence is emerging of a lack of shared understanding of what constitutes appropriate family involvement and how to best incorporate it into services [9]. Such discord is problematic, as it can impact staff attitudes and the general organisational culture toward family work.[10] This, in turn, has implications for resource allocation and intervention delivery, particularly if there is disagreement about the aim or value of conducting it.[11,12]

A recent review by members of our team identified multiple barriers to the implementation of family involvement at the individual, team and organisational level.[13] These barriers were common across intervention models and international settings. A particularly challenging setting is acute treatment, which typically involves admission to hospital for inpatient treatment or a crisis intervention in the community. Clinician reports indicate numerous difficulties in implementing family involvement in these contexts, which are often characterised by a strong focus on risk reduction and crisis management.[14]

Revisiting the concepts underlying family work seems timely as it may bring us a step closer to understanding how to implement it in a way that is in keeping with the values of mental health organisations, users of their services and families. This review seeks to explore the diversity across different family involvement models and to consider how their underlying theoretical backgrounds might impact on how they are delivered and received today. We investigated the following questions:

- (1) Which family involvement models are used in general adult acute mental health settings?
- (2) What is the theory or rationale underlying family involvement models?
- (3) What are the components of the models?
- (4) What is the role of patients and family in the delivery of the models?

METHOD

For this review, we did not aim to produce an exhaustive list of every existing family involvement model. Instead, we set out to find distinct approaches that represented the

1
2
3 diversity of the models that are used today. A conceptual review,[15] which enables the
4 exploration of the breadth of concepts in a given area was considered the most appropriate
5 methodology to answer these research questions.[16-19] This review was pre-registered on
6 PROSPERO (CRD42016032749).
7

8 **Search Strategy and Selection Criteria**

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10 A wide search strategy was employed, including a systematic search of electronic databases
11 (Embase, MEDLINE, PsycINFO, BNI, CINAHL and AMED) for descriptors of “family/carers”
12 “mental health” “model/approach” and “setting” and hand searches (see appendix one). AD
13 conducted the searches in consultation with SS and experts in the field. As described below,
14 the searches and analyses were iterative and the chosen key models were finalised during
15 the first stage of analysis.
16

17 We included (1) key texts containing an original description of a family involvement model
18 that (2) referred to the management of an acute mental health situation or the treatment of
19 “severe mental illness” that could be started during the acute phase (3) with a clear
20 description of how families are involved in the patient’s treatment and (4) the primary focus
21 was general adult mental health (ages 18 - 65).
22

23 Papers were excluded if (1) the word “carer” was being used to refer to paid staff members,
24 (2) the primary focus was on specialist services, (3) they were a description of a family
25 therapy model rather than a programme designed for family involvement in acute mental
26 health treatment or (4) it was not possible to obtain an English-language description,
27 although non-English texts were translated whenever possible.
28

29 The criteria meant that we could only include models where the primary focus was to involve
30 family members in order to support the patient’s care in acute settings. Whilst other
31 approaches to involving families exist, they were considered to be beyond the scope of the
32 current review.
33

34 **Data Analysis**

35

36 A multidisciplinary review team was formed to minimise biases in the searches and
37 analyses.[15] This composed of the lead researcher (AD, a doctoral researcher), a research
38 psychologist (SS), two clinical/academic psychiatrists (DG and SP), three individuals with
39 lived experience of acute mental health treatment, either as patients or as family members
40 (KB, GB and SC) and a clinical nurse manager, who also has research experience (PM).
41 The review team worked most closely on steps two and three below.
42

43 A narrative synthesis was conducted to reach a thorough conceptual understanding of family
44 involvement models.[20] The steps described below were highly iterative:
45

46
47 1. To develop a preliminary synthesis, found texts were clustered into categories of family
48 involvement models. The clustered groups were expanded and collapsed until the family
49 involvement models were broadly similar within each group and sufficiently different from the
50 other groups. Then, the key texts were identified within each group by reference screening,
51 citation checking and snowballing to find original descriptions of the approach. The final
52 inclusion decision was made after discussions with colleagues and experts in the field.
53

54 Alongside this, the theoretical references of the models were identified by extracting the
55 change processes and reasons for intervention development described in the texts, as well
56 as reference screening, reading widely around the subject area and consulting experts. The
57 chosen family involvement models were mapped on to the identified theories.
58
59
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2. Components of the included studies were identified by extracting authors' descriptions of how the model is carried out and clustering the text into similar methods. Similarities and differences were then compared across the models.

3. We explored the role of patients and carers within and between the models using thematic analysis.[21] A selection of family involvement models were examined in depth, ensuring there was representation across the identified theoretical references. Analysis of the emerging key themes was conducted iteratively after multiple reflective discussions.

4. As well as utilising our own multidisciplinary review teams, several measures were taken to ensure robustness of the synthesis. This included numerous consultations with a wider team of around 30 researchers, an expert in Family Intervention, two service user research groups (SUGAR, the Service User and carer Group Advising on Research; and SURF, the North London Service User Research Forum), and a Social Psychiatry expert academics meeting. The ROBIS (Risk Of Bias In Systematic reviews) tool was used to guide our methodology, although quality assessment of the included studies themselves was not considered appropriate for this review of concepts.[22]

RESULTS

The analysis was built up at each stage from (1) identifying distinct models (2) mapping the models to their theoretical references (3) comparing the model components and (4) exploring the role of patients and carers in the delivery of the approaches.

1. Key models

We identified six distinct family involvement models from sixteen key sources (table 1). This included four key family psychoeducation models, which were clustered due to the similarity of their underlying approach. The PRISMA flow diagram (figure 1) depicts our selection process.[23]

As will be described, some of the models (e.g. family psychoeducation) were originally developed for the treatment of schizophrenia or psychosis and then adapted to be utilised more widely whereas others were less focused on a particular service context or diagnostic category.

[Figure 1: Study selection]

Model	Country	Description
<i>Calgary Family Assessment and Intervention Models</i> [24]	Canada	Guidelines for family nursing practice and assessment that draw upon systems, communication, and change theory. In acute care, interventions may target cognitive, affective and behavioural domains of family functioning to invoke change. Staff are trained to use systemic tools such as genograms for the assessment of social relationships.
<i>ERIC (Equipe Rapide d'Intervention de Crise)</i> [25]	France	Nurses, doctors and psychologists work together as a large multidisciplinary team in a mobile service. Brief psychotherapy is provided, usually in the patient's home, with the aim of "enveloping" (containing) the crisis. There is strong emphasis on the role of communication and the competence of

		the family unit to deal with future crises.
1 2 3 4 5 6 7 8 9 10 11 12	<i>Family Psychoeducation Models</i> [26-31]	UK, USA
13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28	<i>Family Systems Approach (SYMPA)</i> [32-34]	Germany
29 30 31 32 33 34	<i>Open Dialogue</i> [35-37]	Finland
35 36 37 38 39 40 41 42 43 44 45 46 47 48 49 50 51 52 53 54 55 56 57 58 59 60	Somerset Model [38,39]	UK

Table 1: Family involvement models in acute mental health care

2. Theory mapping

We then explored how the models relate to their most commonly cited theoretical influences, which included systems theory, the diathesis-stress model and postmodern theories. There were some overlaps in the theoretical references underpinning the models, as illustrated in figure 2.

[Figure 2: The placement of family involvement models within the diathesis-stress, systems and postmodern theories.]

Systems Theories

Systems theories (e.g. General Systems Theory and Cybernetics)[40-42] are commonly used frameworks for broadly understanding how all systems function and the importance of interactions in those systems. In psychiatry, a major application of these theories has been systemic family therapy.[43-45] Here, the broad principles posit that there is an issue within the family system and that one person within this becomes the designated “patient” presented to services. The professional’s role is to work with the whole family to influence the processes that contribute to the patient’s mental state.

1
2
3 A minority of the examined models offer traditional systemic family therapy as a
4 supplementary, intensive service for particular families.[32,33,35] However, the general
5 influence of systems theories is substantial across the models. Historically, whilst some
6 models were developed in part as a reaction to the perceived “blaming” attitude of systemic
7 family therapy,[26,28,29] others used systemic principles as a guideline to set-up family-
8 inclusive services.[25,32-34,38,39] Notably, the majority of models utilise systemic
9 techniques in their everyday practice, such as constructing genograms (social network
10 diagrams) to understand the patient’s social environment[24,32,38,39] and using therapeutic
11 techniques such as circular questioning.[28]
12

13 *The Diathesis-Stress Theory*

14
15 The diathesis-stress model posits that people with schizophrenia have an underlying
16 physical vulnerability to developing symptoms, the risk of which only manifests if the person
17 experiences excessive environmental stress.[46] Research into potential environmental
18 stressors highlighted several concepts of harmful (or helpful) communication patterns within
19 families.[47]
20

21 Based on this theory, multiple family involvement models were developed to address the
22 underlying biological causes of schizophrenia by using medication as well as providing
23 support and “psychoeducation” to families to teach them the diathesis-stress model and
24 reduce stressful communication that could exacerbate symptoms. [26-31]
25

26 One commonly accepted theory of communication is “Expressed Emotion” (“EE”), which
27 suggests that levels of *hostility*, *criticism*, *overinvolvement*, and *warmth* can affect a person’s
28 likelihood of relapse ”.[47,48] While some models intervened directly in EE communication
29 (e.g. [27-28]), others focused more on developing general communication skills within the
30 family unit to encourage expression and improve problem-solving. [26]
31

32 Later, psychoeducation models were developed to include other mental and physical health
33 conditions [49-52] and alternative modes of delivery, including mobile crisis teams [53] and
34 online interventions, including those focused on family members’ own needs.[54,55] In
35 addition, some services have incorporated other concepts such as recovery and peer
36 support.[56]
37

38 Whilst the clearest influence of the diathesis-stress theory is on family psychoeducation
39 models,[26-31] arguably its elements exist in all models that take place within a medical
40 system. For example, almost all of the models routinely recommend medication along with
41 psychological support and social interventions (e.g. [32-34]).
42

43 *Postmodern Theories*

44
45 Postmodern approaches to mental health are often critical of commonly-accepted narratives
46 of “mental illness”. [57] Influential theories within this sphere include social constructionism
47 and constructivism, which broadly posit that mental health problems only exist in social
48 contexts and so their solutions can only emerge within those contexts.[58-60] There are
49 some overlaps with systemic theories, particularly in terms of the importance of viewing the
50 patient within their social context. An area of difference is less focus on interactions within
51 the “system” and more on the individual perspectives people have on their own problems. As
52 a result, postmodern approaches tend to focus less on particular interventions and more on
53 working with uncertainty during the therapeutic process. Whilst the rise in popularity in the
54 1960s is well documented (e.g. [58,59,61]), these viewpoints were not translated to widely
55 used family involvement models, and largely fell out of favour for more medically focused
56 approaches. However, some models developed from postmodern and systemic ideas, often
57 as a reaction to more medical theories.[24,32-37]
58
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Whilst pure postmodernism rejects biological explanations, these models took a more integrated approach, incorporating postmodern theories and practices (e.g. [62-64]) into existing medical systems. Common features included strong emphasis on the wider social context [35-37] and prominence given to individual narratives and explanations [24,35,36] rather than emphasising diagnoses or highly structured treatment models, which could be viewed as imposing “absolute truths” or world views.

3. Synthesis of the components of the approaches

Considering the rich and divergent theoretical background of family involvement models, we examined how these theories related to the components of the models. The section below refers to original descriptions of key family involvement models. In current practice, models have been adapted in countless ways to include different concepts. This includes variation to the methods of service delivery and the inclusion (or exclusion) of particular therapeutic components. However, the most common components across the original descriptions are summarised in table 2 and the following section.

	Communication / Language Use	Joint Decision-Making	Support For The Family	Wider Social Network	Medication Use	Specialist Teams/Staff	Whole System Approach
Calgary Family Assessment and Intervention Model [24]	√√	√√	√√	√	√	–	√√
ERIC (Equipe Rapide d'Intervention de Crise) [25]	√√	√	√√	√	√	–	√√
Family Psychoeducation Models [26-31]	√√	√	√√	–	√√	√√	–
Family Systems Approach (SYMPA) [32-34]	√√	√√	√	√	√	–	√√
Open Dialogue [35-37]	√√	√√	√	√√	√	–	√√
Somerset Service Model	√	√	√√	√	√	–	√√

[38,39]

Table 2: Common components of family involvement models

(key: \checkmark Strongly emphasised in model; \checkmark Present in the model, not a key feature; – Relatively less or no emphasis)

Communication/Language Use

Communication and language use were strongly emphasised across all models. Models adhering to the diathesis-stress theory intervened in EE or other aspects of communication as a tool in relapse prevention.[47,48] In Open Dialogue and ERIC, whilst the theoretical basis was very different, the dialogue between and within participants was theorised as the main driver of change.[25,35-37] Systemic approaches such as the Calgary model trained staff in communication to improve families' service experience [24] whilst in SYMPA staff were trained to avoid diagnostic labels, as they could disempower patients and encourage a "psychiatric career" identity.[32,33]

Joint Decision-Making and the Role of Experts

All the models emphasised the need to make decisions jointly, although the emphasis on experts differed. Models based on the diathesis-stress theory, which are more medical in nature, emphasised the importance of experts who provide "information, advice and guidance" [28]. However, this approach existed in other models, but was not acknowledged as openly. Other models "incompatible" with "the illness concept inherent in the idea of vulnerability and the strong focus on compliance with psychopharmacological treatments" (p.377, [33]) still described how clinicians needed to "negotiate" various aspects of the treatment with the patient and their family.[32-34] Postmodern-influenced models minimised professionals' role in treatment decisions, and made all clinical decisions jointly with the patient and their wider social network. This often meant that the professionals had to "tolerate uncertainty" in the treatment process.[35-37]

Support for the Family Themselves

Some models were developed directly in response to families' stated needs for support and involvement.[27,28,38,39] This could for example prevent the build-up of problems which could manifest as poor communication.[27] More systemic or postmodern influenced models were less focused on family support, and rather saw the involvement of the patient's wider social network as a necessary tool in understanding their social context.[32-34]

Wider Social Network Involvement

The involved "family" differed across the models. Psychoeducation models generally focused on the people the patient lives with (and therefore interacts with the most), meaning it was largely aimed towards parents and partners. [26-31] This was sometimes a deliberate decision based on previous lack of utility when involving extended relatives and friends.[29] Whilst some systemic models also referred to the family in this context [25] others used the term "family" more widely to refer to any members of the patient's "problem determined-system".[34] Open Dialogue, which focuses heavily on interactions within the wider social network placed importance on all its members, including friends, family, neighbours and colleagues.[35-37]

Medication Use

Medication use featured in all models. Approaches that derive more from the diathesis-stress model considered medication to be an important component and the family were sometimes seen as a core resource to help with maintaining adherence.[26,29-31] Whilst the SYMPA model favoured a systemic understanding of the patient's situation, the importance of "negotiation" with the patient regarding medication was emphasised.[32-34] Other systemic and postmodern-influenced models placed less emphasis on its use in the examined texts.[24,25] The greatest variation was in Open Dialogue, as patients were not given medication at the outset. If their condition did not improve, they were offered a low dose, with the aim to taper or discontinue its use over time.[35-37]

System organisation

Finally, a major area of difference was the way the service was organised to deliver family involvement. Models based on the diathesis-stress theory usually required a small group of staff members to be trained as family involvement specialists who could manage the complexities of patient-family work.[26-31] Conversely, systemic models required whole teams to be trained in the principles of family involvement.[24,32-39] Whilst specialist family training was still required, this was applied across the service and was not solely the responsibility of a smaller team.

4. The role of patients and families

For the final research question, a thematic analysis[21] was conducted on the descriptions of the role of patients and families in the delivery of the models (summarised in table 3). The process was highly iterative and included multiple discussions with patients, family members and professionals. This analysis has also been supplemented by existing literature on this topic to reflect wider developments.

Theme	Subthemes
1. Families Are a Resource	
2. Linear Roles and Relationships	2.1. <i>There is a "patient" and a "carer"</i> 2.2. <i>Families want to help</i> 2.3. <i>Family involvement is always beneficial</i>
3. Risk of Identity Loss	
4. Implementation vs. Choice	

Table 3. Themes and subthemes relating to the role of patients and families in family involvement models

1. Families Are a Resource

Families were conceptualised as a resource in a number of ways. They were often seen as "*potentially competent partners*" ([65] cf. [35]) in the stabilisation phase of the patient and in adherence to clinical procedures.[25-27,29,31] They were also perceived as a source of information about the patient's situation - whether directly or by observation.[26,32,33]

However, it was unclear whether family members were given the opportunity to refuse involvement whilst acknowledging the potential feelings of guilt that can emerge from this. Success of a model often seemed to depend on the willingness of the family to accept their "helpful" or "carer" role and to engage with the techniques led by the professionals. Often, there were descriptions of how to engage unwilling family members).[26,31,35,36] This was addressed in some models by emphasis on tools for family members to consider their own needs [e.g. [26, 38-39].

2. Linear Roles and Relationships

2.1. *There is a “patient” and a “carer”*: The relationship between the family and the individual accessing services was presented linearly, unless it was referring to co-dependency.[28] Even in systemic approaches that had circular causation as a theoretical reference, there was a clear, unidirectional “carer” and “patient” role. [24,25,32-34] The possibility of reciprocal support or a more egalitarian or independent relationship was not explicitly described in the examined models. This was also highlighted as an issue by individuals who hold mutual “patient” and “carer” roles during the analysis and consultation process. The role of reciprocity in caregiving in mental health is however explored in other research literature [66] and may hold a more prominent role in everyday clinical practice.

2.2. *Families want to help*: Related to this, it was generally assumed that families either want involvement in the patient’s treatment, or do not want it because they have been let down by professionals in the past.[26,38,39] This in accordance with wider literature in the area, which highlights difficulties families experience when requesting involvement and information in clinical settings.[67,68] An alternative view that emerged from family members during the analysis process was that families might care for a relative but not want to feel responsible for their treatment. This was not explored in the examined texts but wider literature suggests a range of tools to support family members, which may help to overcome such difficulties in practice. [69]

2.3. *Family involvement is always beneficial*: Moreover, whilst it was acknowledged that not everyone has supportive family members and that some relationships might be complicated, it was generally assumed that the involvement of family would be beneficial.[31,35,36] This idea is widely supported in wider literature (e.g.[1,2]). However, as described next, the analysis process also indicated potential harms of involvement, which were often not explored in the examined texts. These ideas largely emerged from discussions of the personal lived experiences of patients and family members during the analysis process.

3. Risk of Identity Loss

Considering the inherent vulnerability of being an individual in acute care, the positive and negative implications of involving others seemed greater. Clearly, family and friends could be a source of comfort and support in a difficult setting. However, sharing one’s private information in a setting where they are the “patient in need” could also risk altering their roles and relationships after they left acute treatment. In approaches with a wider social network approach, this potentially carried a higher risk. For example, colleagues may be invited to treatment meetings.[35-37] It seemed important to consider whether the patient in crisis could make a fully informed decision about the consequences of this and the possible impact this could have when they return to work.

Moreover, a general lack of accounts from patients themselves across the models meant that the “patient” could sometimes be described as a passive recipient of the interventions. Examples of individuals taking a more active role included psychoeducation that enlisted patients to share their own accounts[26] and patients being a core part of joint decision-making.[35-37]

4. Implementation vs. Choice

Considering these points, we contemplated the role of patient choice in family involvement and how the structure of service organisation might affect this. If a whole service is set up to operate on the principles that family involvement is fundamental to psychiatric treatment, this makes it more likely to be implemented, as all staff are fully trained in facilitating it.[24,32-39] However, depending on the delivery of the approach, this also has greater potential to

1
2
3 weaken the patient's voice in the matter, making them feel pressured to involve others in a
4 process they might have preferred to remain private. Conversely, if there are only specialist
5 family involvement teams within a larger system, this can soon become an underused
6 "niche" service. In this case, the specialist team must rely on external factors such as
7 managers and other colleagues seeing value in their approach, providing resources and
8 collaborating to identify and refer "suitable" families to the service, all of which can result in
9 lower implementation.[13,26-31] Overall, whilst there may be no ideal approach to service
10 organisation, the way "choice" is presented appeared to be an important factor.
11

12 13 DISCUSSION

14
15 This review broadly identified key family involvement models in acute mental health
16 treatment and considered how their theoretical references are related to their delivery. From
17 this, we considered how patients and families might be impacted. Despite major theoretical
18 differences, we found many similarities in the components of the models, which raised the
19 question: what is the intended aim when involving families and is it important to specify this?
20 Namely, should all models be considered the same or is the theoretical basis an important
21 aspect of delivery? Perhaps, as has been suggested for individual psychotherapy,
22 nonspecific factors (e.g. the therapeutic relationship) determine the usefulness of the chosen
23 model.[70] However, it may be important to place the model within its wider theoretical
24 context to aid staff training and understanding, particularly in light of difficulties with
25 implementation in this field.[3]
26

27 For example, there may be a conflict in how staff should conceptualise the "patient" and
28 "family" roles and relationships. MacFarlane highlights how clinicians might struggle to be
29 simultaneously family-positive and inclusive despite being taught that they are at least
30 partially responsible for the patient's problems.[71] Acknowledging these tensions and
31 finding a way to integrate divergent world views may increase the likelihood of offering family
32 involvement more consistently across services.
33

34 It is also important to consider that overall, a significant aspect of implementation is how well
35 a model fits with a service's existing values.[72] Family psychoeducation is most strongly
36 aligned with the existing biopsychosocial medical model, and this might be one reason why it
37 fits more easily into existing services than postmodern or systemic models. The
38 fundamentals of the latter approaches might be harder to train clinicians who have primarily
39 been taught the biopsychosocial model, and to obtain resources through regular funding
40 structures which prioritise medically-focused clinical outcomes.
41

42 In considering implementation, the importance of patient and family experience should also
43 be emphasised. For example, choice emerged as a significant consideration in our review.
44 Too much focus on system-wide implementation could mean more likelihood of some
45 patients feeling coerced into involving others during what is preferred to be a private
46 process. This is of particular importance considering the potential harmful impacts of
47 assuming individuals hold particular roles in their relationship. For example, a mother having
48 a mental health crisis might not wish for her son to be present as a "carer" in her most acute
49 phase, even if he is of adult age. This risks not only taking away her role as a person who
50 holds authority and respect (a "parent") but it might impact on the dynamics of their
51 relationship after the acute episode has subsided. This notion corresponds with Goffman's
52 theories of the risk of identity loss in inpatient settings.[61]
53

54
55 Our review also indicated the potential for family members to feel disempowered by being
56 viewed as a resource for services. This point was recently raised by Meijer and colleagues,
57 who highlight the tension of being imposed the role of "carer" whilst having one's own goals
58 and needs to attend to.[73] Rugkåsa's comprehensive review of elements of coercion in
59
60

1
2
3 caring also makes the point that families may wish to be less involved in the care of their
4 relative but fear the consequences of doing so.[74]
5

6 It is important to note here that a large body of research evidence supports the view that
7 many families wish to have significantly more involvement, particularly in crisis
8 contexts.[75,76] However, this review highlights the challenges of accommodating diverse
9 needs in an already complex service setting. Overall, the offer of family involvement requires
10 a delicate balance on the part of service leaders to support availability whilst maximising
11 patients' and families' decision-making in the process.
12

13 **Strengths and Limitations**

14
15 This review has a number of strengths and limitations to consider. To our knowledge this is
16 the first conceptual review that has actively included people with lived experience of mental
17 health services alongside academics and clinicians in the review team. This has allowed for
18 in-depth integrations of personal and professional experiences of family involvement. This
19 has contributed to a deeper understanding of not just the concepts present in each model,
20 but also what is *not* explained. From the latter, potential problems in the delivery of
21 interventions were revealed. Research into patient safety emphasises the benefits of
22 involving people with lived experience in identifying unknown latent harms.[77]
23

24 Although we conducted a systematic search, our findings are by no means an exhaustive list
25 of all existing family involvement models. We avoided this for pragmatic reasons: in practice,
26 the implementation of family involvement models can vary greatly, resulting in an infinite
27 number of ways each component can be delivered. Investigating these infinite nuances will
28 not necessarily lead to a better understanding of the field as a whole. Instead, a broad
29 understanding of the diversity of the models that exist, and their common concepts, signifies
30 the basis of family involvement in most settings.
31

32 Finally, due to the emphasis on published articles and manuals, the majority of literature was
33 based in Europe, the USA and Australasia, or what is often referred to as the "Western"
34 medical system. This common problem can impact how relevant the results are cross-
35 culturally.[78] Moreover, there may be an influence of the local context on the development
36 and delivery of the included models, which might not translate to other settings. For
37 example, rural environments might have more traditional family support structures than
38 urban settings, affecting the nature of the involvement that can take place. However, when
39 screening articles we struck by how globalised family involvement approaches had become,
40 particular the adaptation of family psychoeducation to a number of international contexts.
41 [79-81] How well this approach integrates with existing belief systems is a matter for another
42 enquiry.
43
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45 **Conclusions**

46
47 Although family involvement models have been developed in the context of diverse
48 theoretical perspectives and socio-political events, there are many commonalities in their
49 components. Despite these commonalities, it must be acknowledged that the models are
50 different in nature and underlying purpose. To enhance staff training and support
51 implementation, there may be value in discussing the fundamentals of why family
52 involvement is conducted, how it might be experienced by patients and families and how this
53 relates to staff members' own perspectives. We therefore encourage further discussion of
54 the differences and similarities between the various models and theories, taking into
55 consideration different ideas about the nature of mental health and the purpose of involving
56 families in these contexts.
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COMPETING INTERESTS

None declared.

DATA SHARING STATEMENT

There are no additional unpublished data to share.

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AUTHORS' CONTRIBUTIONS

AD designed the study, conducted searches and data extraction (in consultation with SS and SP), led on the analysis and prepared the manuscript. All authors contributed to the analysis, critically reviewed the paper and approved the final manuscript. SP and SS provided overall guidance and supervision for the study.

REFERENCES

- 1 Pharoah F, Mari J, Rathbone J, *et al*. Family intervention for schizophrenia. *Cochrane Database of Systematic Reviews* 2010;**12**.
- 2 Garety P, Pilling S, Bebbington P, *et al*. Psychological treatments in schizophrenia: I. Meta-analysis of family intervention and cognitive behaviour therapy. *Psychol Med* 2002;**32**:763–82. doi:10.1017/S0033291702005895
- 3 Ince P, Haddock G, Tai S. A systematic review of the implementation of recommended psychological interventions for schizophrenia: Rates, barriers, and improvement strategies. *Psychology and Psychotherapy: Theory, Research and Practice* Published Online First: 5 November 2015. doi:10.1111/papt.12084
- 4 Macfarlane MM. *Family Therapy and Mental Health*. Routledge 2013.
- 5 Mairs H, Bradshaw T. Implementing family intervention following training: what can the matter be? *Journal of Psychiatric and Mental Health Nursing* 2005;**12**:488–94. doi:10.1111/j.1365-2850.2005.00871.x
- 6 Worthington A, Rooney P. The Triangle of Care; Carers included: A guide to best practice in acute mental health care. 2010;:1–32.
- 7 Hofmann SG, Tompson MC. *Treating Chronic and Severe Mental Disorders: A Handbook of Empirically Supported Interventions*. Guilford Press 2002.
- 8 Eisler I. A rose by any other name. *Journal of Family Therapy* 2005.
- 9 Kavanagh DJ. What the Problem May Be With Family Intervention ... and With Dissemination More Generally: A Commentary. *Australian Psychologist* 2016;**51**:69–72. doi:10.1111/ap.12205
- 10 Fadden G, Birchwood M, Lefley H, *et al*. British models for expanding family psychoeducation in routine practice. *Family interventions in mental illness: International perspectives* 2002;:25–42.
- 11 Brooker C, Butterworth C. Working with families caring for a relative with schizophrenia: the evolving role of the community psychiatric nurse. *International Journal of Nursing Studies* 1991;**28**:189–200.
- 12 Brent BK, Giuliano AJ. Psychotic-spectrum illness and family-based treatments: a case-based illustration of the underuse of family interventions. *Harvard Review of Psychiatry* 2007;**15**:161–8.
- 13 Eassom E, Giacco D, Dirik A, *et al*. Implementing family involvement in the treatment of patients with psychosis: a systematic review of facilitating and hindering factors. *BMJ Open* 2014;**4**:e006108–8. doi:10.1136/bmjopen-2014-006108
- 14 Fadden G. Overcoming barriers to staff offering family interventions in the NHS. In: *A Casebook of Family Interventions for Psychosis*. John Wiley and Sons 2009. 309.
- 15 Lilford RJ, Richardson A, Stevens A, *et al*. Issues in methodological research: perspectives from researchers and commissioners. *Health Technology Assessment* 2001;**5**. doi:10.3310/hta5080

- 1
2
3 16 Priebe S, Dimic S, Wildgrube C, *et al.* Good communication in psychiatry – a
4 conceptual review. *European Psychiatry* 2011;**26**:403–7.
5 doi:10.1016/j.eurpsy.2010.07.010
6
7 17 Chow WS, Priebe S. Understanding psychiatric institutionalization: a conceptual review.
8 *BMC Psychiatry* 2013;**13**:1–1. doi:10.1186/1471-244X-13-169
9
10 18 Priebe S, Omer S, Giacco D, *et al.* Resource-oriented therapeutic models in psychiatry:
11 conceptual review. *The British Journal of Psychiatry* 2014;**204**:256–61.
12 doi:10.1192/bjp.bp.113.135038
13
14 19 Leamy M, Bird V, Le Boutillier C, *et al.* Conceptual framework for personal recovery in
15 mental health: systematic review and narrative synthesis. *The British Journal of*
16 *Psychiatry* 2011;**199**:445–52. doi:10.1192/bjp.bp.110.083733
17
18 20 Popay J, Roberts H, Sowden A, *et al.* Guidance on the conduct of narrative synthesis in
19 systematic reviews. 2006.
20
21 21 Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in*
22 *Psychology* 2006;**3**:77–101. doi:10.1191/1478088706qp063oa
23
24 22 Whiting P, Savović J, Higgins JPT, *et al.* ROBIS: A new tool to assess risk of bias in
25 systematic reviews was developed. *Journal of Clinical Epidemiology* 2016;**69**:225–34.
26 doi:10.1016/j.jclinepi.2015.06.005
27
28 23 Moher D, Liberati A, Tetzlaff J, *et al.* Preferred Reporting Items for Systematic Reviews
29 and Meta-Analyses: The PRISMA Statement. *Ann Intern Med* 2009;**151**:264–9.
30 doi:10.7326/0003-4819-151-4-200908180-00135
31
32 24 Wright LM, Leahey M. *Nurses and Families: a guide to family assessment and*
33 *intervention (6th ed)*. F A Davis Philadelphia. 2013.
34
35 25 Zeltner L, Ampelas J-F, Mallat V, *et al.* Prise en charge de crise et enveloppe
36 langagière. *Thérapie Familiale* 2002;**Vol. 23**:357–66. doi:10.3917/TF.024.0357
37
38 26 Falloon IRH. *Family care of schizophrenia: a problem-solving approach to the treatment*
39 *of mental illness*. Guilford Press New York.1984.
40
41 27 Leff J, Berkowitz R, Eberlein-Vries R, *et al.* A controlled trial of social intervention in the
42 families of schizophrenic patients. *The British Journal of Psychiatry* 1982;**141**:121–34.
43 doi:10.1192/bjp.141.2.121
44
45 28 Kuipers L, Leff J, Lam D. *Family Work for Schizophrenia*. RCPsych Publications 2002.
46
47 29 Anderson CM, Reiss DJ, Hogarty GE. *Schizophrenia and the Family*. Guilford Press
48 1986.
49
50 30 Hogarty GE, Anderson CM, Reiss DJ, *et al.* Family Psychoeducation, Social Skills
51 Training, and Maintenance Chemotherapy in the Aftercare Treatment of Schizophrenia:
52 I. One-Year Effects of a Controlled Study on Relapse and Expressed Emotion. *Archives*
53 *of General Psychiatry* 1986;**43**:633–42. doi:10.1001/archpsyc.1986.01800070019003
54
55 31 Barrowclough C, Tarrrier N. *Families of Schizophrenic Patients*. Nelson Thornes 1992.
56
57 32 Schweitzer J, Ginap C, Twardowski Von J. Training psychiatric teams to do family
58 systems acute psychiatry. *Journal of Family Therapy* 2007;**29**:3–20. doi:10.1111/j.1467-
59
60

- 1
2
3 6427.2007.00366.x
4
5 33 Schweitzer J, Zwack J, Nicolai E, *et al.* Family systems psychiatry: principles, good
6 practice guidelines, clinical examples, and challenges. *American Journal of*
7 *Orthopsychiatry* 2007;**77**:377–85. doi:10.1037/0002-9432.77.3.377
8
9 34 Haun MW, Kordy H, Ochs M, *et al.* Family systems psychiatry in an acute in-patient
10 setting: the implementation and sustainability 5 years after its introduction. *Journal of*
11 *Family Therapy* 2013;**35**:159–75. doi:10.1111/j.1467-6427.2012.00586.x
12
13 35 Seikkula J, Alakare B, Aaltonen J. Open dialogue in psychosis I: An introduction and
14 case illustration. *Journal of Constructivist ...* 2001;**14**:247–65.
15 doi:10.1080/10720530125965
16
17 36 Seikkula J, Alakare B, Aaltonen J. Open dialogue in psychosis II: A comparison of good
18 and poor outcome cases. *Journal of Constructivist ...* 2001;**14**:267–84.
19 doi:10.1080/10720530126129
20
21 37 Seikkula J, Aaltonen J, Alakare B, *et al.* Five-year experience of first-episode
22 nonaffective psychosis in open-dialogue approach: Treatment principles, follow-up
23 outcomes, and two case studies. *Psychotherapy Research* 2006;**16**:214–28.
24 doi:10.1080/10503300500268490
25
26 38 Stanbridge R, Burbach F. Developing family-inclusive mainstream mental health
27 services. *Journal of Family Therapy* 2007;**29**. doi:10.1111/j.1467-6427.2007.00367.x
28
29 39 Stanbridge R, Burbach F. Establishing family inclusive acute inpatient mental health
30 services: a staff training programme in Somerset. *Journal of Family Therapy*
31 2009;**31**:233–49. doi:10.1111/j.1467-6427.2009.00467.x
32
33 40 The history and status of general systems theory. *Academy of Management Journal*
34 1972;**15**:407–26.
35
36 41 Wiener N. *Cybernetics Or Control and Communication in the Animal and the Machine*.
37 MIT Press 1961. doi:10.2307/41885113
38
39 42 Ashby WR. *An Introduction to Cybernetics*. London: : Chapman & Hall 1956.
40
41 43 Selvini-Palazzoli M, Boscolo L, Cecchin G, *et al.* *Paradox and counterparadox: A new*
42 *model in the therapy of the family in schizophrenic transaction (tsl., EV Burt)*. New York:
43 Jason Aronson 1978.
44
45 44 Haley J, Erickson MH. *Uncommon therapy*. Norton New York 1973.
46
47 45 Minuchin S. *Families and therapy*. Structural family therapy in theory and practice
48 (Swe.) ... 1974.
49
50 46 Zubin J, Spring B. Vulnerability: A new view of schizophrenia. *Journal of Abnormal*
51 *Psychology* 1977;**86**:103–26. doi:10.1037/0021-843X.86.2.103
52
53 47 Brown GW, Birley JL, Wing JK. Influence of family life on the course of schizophrenic
54 disorders: A replication. *The British Journal of Psychiatry* 1972;**121**:241–58.
55 doi:10.1192/bjp.121.3.241
56
57 48 Vaughn CE, Leff JP. The influence of family and social factors on the course of
58
59
60

- 1
2
3 psychiatric illness. A comparison of schizophrenic and depressed neurotic patients. *The*
4 *British Journal of Psychiatry* 1976;**129**:125–37. doi:10.1192/bjp.129.2.125
- 5
6 49 Miklowitz DJ. *Bipolar disorder: A family-focused treatment approach*. 2010.
- 7
8 50 Hutchison SD, Steginga SK, Dunn J. The tiered model of psychosocial intervention in
9 cancer: a community based approach. *Psycho-Oncology* 2006;**15**:541–6.
10 doi:10.1002/pon.973
- 11
12 51 Alloway SC, Toth EL. Effectiveness of a group psychoeducation program for the
13 treatment of subclinical disordered eating in women with type 1 diabetes. *Canadian*
14 *Journal of ...* 2001.
- 15
16 52 Garner DM, Rockert W, Olmsted MP. Psychoeducational principles in the treatment of
17 bulimia and anorexia nervosa. ... *for anorexia nervosa ...* 1985.
- 18
19 53 McFarlane WR, Stastny P, Deakins S. Family-aided assertive community treatment: A
20 comprehensive rehabilitation and intensive case management approach for persons
21 with schizophrenic disorders. *New directions for mental health services* 1992;**1992**:43–
22 54.
- 23
24 54 Sin J, Henderson C, Pinfold V, *et al*. The E Sibling Project—exploratory randomised
25 controlled trial of an online multi-component psychoeducational intervention for siblings
26 of individuals with first episode psychosis. *BMC Psychiatry* 2013;**13**:123.
- 27
28 55 Alvarez-Jimenez M, Alcazar-Corcoles MA, González-Blanch C, *et al*. Online, social
29 media and mobile technologies for psychosis treatment: A systematic review on novel
30 user-led interventions. *Schizophrenia Research* 2014;**156**:96–106.
31 doi:10.1016/j.schres.2014.03.021
- 32
33 56 Heumann K, Janßen L, Ruppelt F. **A pilot study of peer support for relatives of**
34 **individuals with severe mental health problems: Effects on burden and quality of**
35 **life.** *Zeitschrift für Psychiatrie, Psychologie und Psychotherapie* 2016;**64**:45–53.
36 doi:10.1024/1661-4747/a000259
- 37
38 57 Seikkula J, Aaltonen J, Alakare B, *et al*. *Treating psychosis by means of open dialogue.*
39 *The reflective team in action*. New York: Guildford Press 1995.
- 40
41 58 Laing RD. *The divided self: A study of sanity and madness*. London: Tavistock 1960.
- 42
43 59 Foucault M. *Maladie Mentale Et Psychologie*. Univ of California Press 1966.
- 44
45 60 Gergen KJ. The social constructionist movement in modern psychology. *American*
46 *Psychologist* 1985;**40**:266–75. doi:10.1037/0003-066X.40.3.266
- 47
48 61 Goffman E. *Asylums: Essays on the social situation of mental patients and other*
49 *inmates*. Garden City: New York. Anchor Books. 1961.
- 50
51 62 Bakhtin MM. *The dialogic imagination: Four essays*. Austin, TX: University of Texas
52 Press 1990.
- 53
54 63 Bakhtin M, Emerson C. *Problems of Dostoevsky's poetics*. Manchester: Manchester
55 University Press 1984.
- 56
57 64 Moules NJ. *Postmodernism and the Sacred: Reclaiming Connection in Our Greater-*
58
59
60

- 1
2
3 Than-Human Worlds. *Journal of Marital and Family Therapy* 2000;**26**:229–40.
4
5 65 Gleeson J, Jackson H, Stavely H, *et al.* Family intervention in early psychosis. *The*
6 *Recognition and Management of Early Psychosis*. Cambridge: Cambridge University
7 Press 1999.
8
9 66 Horwitz AV, Reinhard SC, Howell-White S. Caregiving as Reciprocal Exchange in
10 Families with Seriously Mentally Ill Members. *Journal of Health and Social Behavior*
11 1996;**37**:149–62. doi:10.2307/2137270
12
13 67 Gray B, Robinson C, Seddon D, *et al.* “Confidentiality smokescreens” and carers for
14 people with mental health problems: the perspectives of professionals. *Health Soc Care*
15 *Community* 2008;**16**:378–87. doi:10.1111/j.1365-2524.2007.00748.x
16
17 68 Jankovic J, Yeeles K, Katsakou C, *et al.* Family Caregivers' Experiences of Involuntary
18 Psychiatric Hospital Admissions of Their Relatives – a Qualitative Study. *PLoS ONE*
19 2011;**6**:e25425–7. doi:10.1371/journal.pone.0025425
20
21 69 Yesufu-Udechuku A, Harrison B, Mayo-Wilson E, *et al.* Interventions to improve the
22 experience of caring for people with severe mental illness: systematic review and meta-
23 analysis. *The British Journal of Psychiatry* 2015;**206**:268–74.
24 doi:10.1192/bjp.bp.114.147561
25
26 70 Ahn H-N, Wampold BE. Where oh where are the specific ingredients? A meta-analysis
27 of component studies in counseling and psychotherapy. *Journal of Counseling*
28 *Psychology* 2001;**48**:251–7. doi:10.1037/0022-0167.48.3.251
29
30 71 McFarlane WR. *Families in the treatment of psychotic disorders*. Harvard Mental Health
31 Letter 1995.
32
33 72 Greenhalgh T, Robert G, Bate P, *et al.* *Diffusion of innovations in health service*
34 *organisations: a systematic literature review*. John Wiley & Sons 2008.
35
36 73 Meijer E, Schout G, Abma T. Am I My Brother's Keeper? Moral Dimensions of Informal
37 Caregiving in a Neoliberal Society. *Health Care Analysis* 2016;:1–15.
38 doi:10.1007/s10728-016-0313-7
39
40 74 Rugkåsa J. Family carers and coercion in the community. *Coercion in Community*
41 *Mental Health Care: International Perspectives*. Oxford University Press 2016.
42
43 75 Wilkinson C, McAndrew S. “I’m not an outsider, I’m his mother!” A phenomenological
44 enquiry into carer experiences of exclusion from acute psychiatric settings. *Int J Ment*
45 *Health Nurs* 2008;**17**:392–401. doi:10.1111/j.1447-0349.2008.00574.x
46
47 76 Walkup J. Family involvement in general hospital inpatient care. 1997;:51–64.
48 doi:10.1002/yd.23319977307
49
50 77 Wright J, Lawton R, O’Hara J, *et al.* Improving patient safety through the involvement of
51 patients: development and evaluation of novel interventions to engage patients in
52 preventing patient safety incidents and protecting them against unintended harm.
53 *Programme Grants for Applied Research* 2016;**4**:1–296. doi:10.3310/pgfar04150
54
55 78 Berry JW, Poortinga YH, Breugelmans SM, *et al.* *Cross-Cultural Psychology*.
56 Cambridge University Press 2011.
57
58
59
60

- 1
2
3 79 Eker F, Harkin S. Effectiveness of six-week psychoeducation program on adherence of
4 patients with bipolar affective disorder. *Journal of Affective Disorders* 2012;**138**:409–16.
5 doi:10.1016/j.jad.2012.01.004
6
7 80 Chan SW-C, Yip B, Tso S, *et al.* Evaluation of a psychoeducation program for Chinese
8 clients with schizophrenia and their family caregivers. *Patient Education and*
9 *Counseling* 2009;**75**:67–76. doi:10.1016/j.pec.2008.08.028
10
11 81 Hacketh V, Spiegel S, Lewis-Fernández R, *et al.* Towards a Cultural Adaptation of
12 Family Psychoeducation: Findings from Three Latino Focus Groups. *Community Ment*
13 *Health J* 2013;**49**:587–98. doi:10.1007/s10597-012-9559-1
14
15
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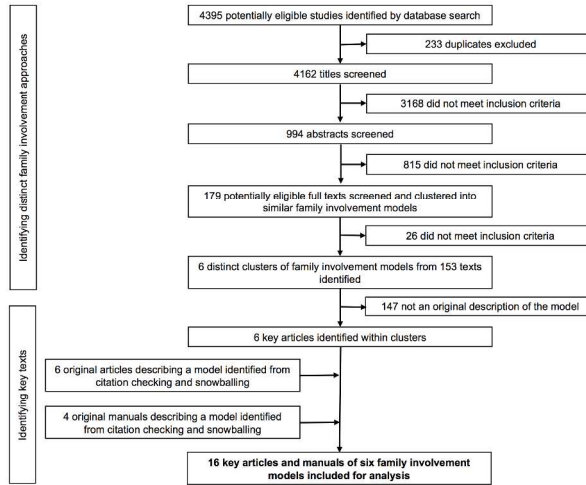


Figure 1: PRISMA flow diagram depicting study selection

297x209mm (300 x 300 DPI)

Review only

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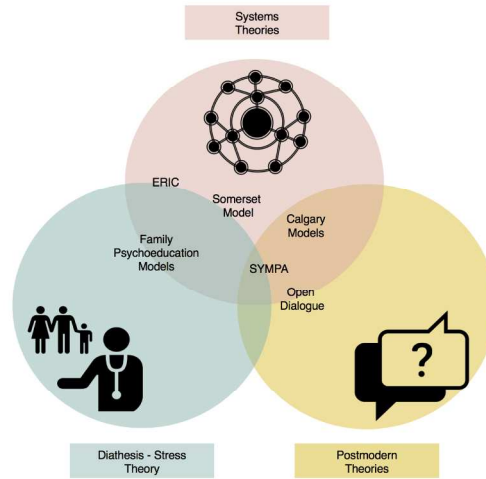


Figure 2: The placement of family involvement models within the diathesis-stress, systems and postmodern theories

297x209mm (300 x 300 DPI)

Review only

Appendix 1: Search Strategy

Embase/MEDLINE

1. 'caregiver'/exp OR 'caregiver' OR carer*:ab,ti OR (social NEXT/2 network*):ab,ti OR famil*:ab,ti
2. 'psychosis'/exp OR 'psychosis' OR 'bipolar disorder'/exp OR 'bipolar disorder' OR 'mental patient'/exp OR 'mental patient' OR (severe* NEXT/2 mental*):ab,ti AND ill*:ab,ti OR ((serious* NEXT/2 mental*):ab,ti AND ill*:ab,ti) OR (service NEXT/1 user*):ab,ti OR (consumer:ab,ti AND mental:ab,ti) OR 'mental disease'/exp OR 'mental disease'
3. 'mental health care'/exp OR 'mental health care' OR 'crisis intervention'/exp OR 'crisis intervention' OR 'involuntary commitment'/exp OR 'involuntary commitment' OR 'inpatient'/exp OR 'inpatient' OR 'psychiatric department'/exp OR 'psychiatric department' OR acute:ab,ti
4. 'medication therapy management'/exp OR 'medication therapy management' OR 'program development'/exp OR 'program development' OR 'patient care planning'/exp OR 'patient care planning' OR 'health services research'/exp OR 'health services research' OR intervention:ab,ti OR involv*:ab,ti OR program*:ab,ti AND ('psychotherapy'/exp OR 'psychotherapy') OR 'psychotherapy'/exp OR 'psychotherapy'
5. #1 AND #2 AND #3 AND #4

PsycINFO

1. DE "Caregivers" OR MM "Social Networks" OR (DE "Family Members" OR DE "Family") OR Carer* OR Famil* OR caregiv*
2. DE "Psychosis" OR DE "Acute Psychosis" OR DE "Affective Psychosis" OR DE "Chronic Psychosis" OR DE "Schizophrenia" OR MM "Bipolar Disorder" OR MM "Cyclothymic Personality" OR MM "Mental Disorders" OR ((Severe* OR serious*) AND Mental* AND Ill*) OR (Service AND User*) OR (Consumer* AND Mental)
3. MM "Involuntary Treatment" OR MM "Psychiatric Hospitalization" OR MM "Psychiatric Hospital Admission" OR MM "Psychiatric Hospital Discharge" OR MM "Psychiatric Hospital Readmission" OR DE "Psychiatric Hospital Admission" OR MM "Psychiatric Units" OR MM "Crisis Intervention" OR acute* OR inpatient
4. DE "Treatment Planning" OR DE "Discharge Planning" OR (DE "Intervention" OR DE "Crisis Intervention" OR DE "Early Intervention" OR DE "Family Intervention" OR DE "Group Intervention") OR (MM "Mental Health Services") OR MM "Program Development" OR involv* OR program* OR interven*
5. #1 AND #2 AND #3 AND #4

AMED

Aysegul Dirik
a.dirik@qmul.ac.uk

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3 exp CAREGIVER/ OR caregiver* OR carer* OR "social network*" OR famil*
4 **AND**
5 PSYCHIATRY AND PSYCHOLOGY/ OR MENTAL DISORDERS/ OR exp
6 PSYCHOTIC DISORDERS/ OR exp SCHIZOPHRENIA/ OR BIPOLAR
7 DISORDER/ OR (severe* AND mental* AND ill*) OR (serious* AND mental* AND
8 ill*) OR "service user*" OR (consumer AND mental)
9 **AND**
10 exp PATIENT CARE PLANNING/ OR exp PATIENT CARE MANAGEMENT/ OR
11 exp METHODS/ OR exp PATIENT ASSESSMENT/ OR exp PATIENT
12 PARTICIPATION/ OR THERAPY/ OR exp PSYCHOTHERAPY/ OR exp FAMILY
13 THERAPY/ OR program* OR intervention* OR invol*
14 **AND**
15 exp MENTAL HEALTH SERVICES/ OR Crisis OR acute* OR exp INPATIENTS/
16 OR inpatient* OR hospital*

18 CINAHL

19
20
21 ((severe* AND mental* AND ill*) OR (serious* AND mental* AND ill*) OR "service
22 user*" OR (consumer AND mental)).ti,ab
23 **OR**
24 MENTAL DISORDERS/ OR PSYCHOTIC DISORDERS/ OR exp
25 SCHIZOPHRENIA/ OR BIPOLAR DISORDER/
26 **AND**
27 exp *HOSPITALS, PSYCHIATRIC/ OR EXP INPATIENTS/
28 OR (inpatient* OR Crisis OR acute*).ti,ab
29 **AND**
30 PATIENT CARE PLANNING/ OR PSYCHOTHERAPY/ OR FAMILY THERAPY/
31 OR (program* OR intervention* OR invol*).ti,ab
32 **AND**
33 (caregiver* OR carer* OR "social network*" OR famil*).ti,ab
34 OR exp CAREGIVERS/
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38 exp CAREGIVER/ OR caregiver* OR carer* OR "social network*" OR famil*
39 **AND**
40 PSYCHIATRY AND PSYCHOLOGY/ OR MENTAL DISORDERS/ OR exp
41 PSYCHOTIC DISORDERS/ OR exp SCHIZOPHRENIA/ OR BIPOLAR
42 DISORDER/ OR (severe* AND mental* AND ill*) OR (serious* AND mental* AND
43 ill*) OR "service user*" OR (consumer AND mental)
44 **AND**
45 exp PATIENT CARE PLANNING/ OR exp PATIENT CARE MANAGEMENT/ OR
46 exp METHODS/ OR exp PATIENT ASSESSMENT/ OR exp PATIENT
47 PARTICIPATION/ OR THERAPY/ OR exp PSYCHOTHERAPY/ OR exp FAMILY
48 THERAPY/ OR program* OR intervention* OR invol*
49 **AND**
50 exp MENTAL HEALTH SERVICES/ OR Crisis OR acute* OR exp INPATIENTS/
51 OR inpatient* OR hospital*
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