

**Review of family therapy and dementia: twenty-five  
years on**

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**Running Title:** Family therapy and dementia

## **Review of family therapy and dementia: twenty-five years on**

### **Abstract**

**Background:** We reviewed the literature on family therapy and dementia to investigate: what is known about the use of family therapy in the context of living with dementia; what are the challenges of working in this context; and what guidelines/ models are available to guide family therapists working with families living with dementia.

**Method:** We searched English language literature from 1992 onwards, classified the resulting papers into broad categories of theoretical, expository; or research (descriptive, quantitative or qualitative), and conducted a narrative review to draw learning points from the identified papers.

**Results:** In total 31 papers were identified; five theoretical, eleven expository; fifteen research. Several papers described methodologies; psychotherapeutic interventions applied to family members; or complex intervention packages in which the role of family therapy could not be separately identified, rather than family therapy. A range of outcomes was investigated, often involving the carer. Several authors suggest areas in dementia care where family therapy is likely to be beneficial.

**Conclusions:** Although the literature on family therapy and dementia has grown over the past 25 years and suggests potentially useful roles for therapy, a number of challenges exist in terms of context, family and therapy itself. There is a need for further research particularly into: how to evaluate the success of therapy; how to ensure treatment integrity; how to make techniques from family therapy available more widely; and how to train the health and social care workforce in working with families.

**Keywords:** dementia, families, family carers, family therapy, people with dementia, systemic therapy

*prepublication draft*

## Introduction

Systemic family therapy (also called family and systemic psychotherapy) is one of the major evidence based therapeutic approaches used within the National Health Service (NHS) in the United Kingdom (UK). The term refers to a range of psychological interventions for individuals, couples and families based on systemic concepts and theory, and designed to help people make changes in their thinking, behavior and understanding to relieve distress, improve the quality of their important relationships, and make positive changes (Association for Family Therapy & Systemic Practice, n/d). This is the definition used in this review.

The term family refers to a group of people who care about each other: they may or may not be related. Thus, although the term family therapy appears to exclude those who live alone or have no family ties or connections, it should be interpreted broadly and it accommodates interest in diversity issues. The term Social GRRRAACCES is a useful acronym which invites consideration of, and reflection on, gender, race, religion, age, abilities, class, culture, ethnicity and sexual orientation (Benbow and Goodwillie, 2010; Divac and Heaphy, 2005).

Family therapy developed across the world primarily in services for families with children and adolescents. The initiative called Improving Access to Psychological Therapies (IAPT) has moved towards making the benefits of talking therapies more generally available in England, and this involves

extending talking therapies to people with physical long-term conditions (Department of Health, 2011) and improving access to talking treatments for older people. The four year action plan for talking therapies (Department of Health, 2011) specifically mentions dementia care and work with carers, as well as the need to be flexible in service provision in terms of offering longer treatment sessions and/ or treatment in different, more appropriate venues. The NICE/ SCIE Dementia guideline includes the use of family therapy in a case example and notes that:

“joint interventions with the person with dementia and family carers, such as family therapy, recognize the fact that the diagnosis does not impact on just one person but on a whole family system ...” (NICE/ SCIE, 2007) (page 88).

Twenty five years ago one of us (SMB) was taking first tentative steps in working with families in a geriatric psychiatry family therapy team setting, and published on using the family life cycle in 1990 (Benbow *et al.*, 1990) followed by a review of family therapy and dementia (Benbow *et al.*, 1993). Personal learning has continued but much has changed since then: dementia has become acknowledged as a global issue in health and social care (Alzheimer's Disease International, 2010; World Health Organisation, 2012). We report here a review of the literature on family therapy and dementia published since 1992 with the aims of identifying: what we know about the use of family therapy in the context of living with dementia; what are the challenges of working in this context; and what guidelines or models are available to guide family therapists working with families living with dementia.

## Method

We searched Medline, CINAHL and PsychInfo from the year 1992 onwards for English language papers using the following strategy: (family therapy or couples therapy or marital therapy) and dementia. This identified 22 papers to which we added a further nine from the reference lists of papers identified and from our own collections, giving a total of 31 papers included in the review.

We intended to assess identified papers for quality using a modified version of the Standard Quality Assessment Criteria for Evaluating Primary Research Papers from a Variety of Fields (Kmet *et al.*, 2004), but the focus of identified papers was broad and to narrow the quality criteria would have excluded many of those identified, similarly classifying papers by psychotherapeutic models limited the number of papers eligible for inclusion. Therefore we opted instead to include all the papers in the review, to classify them into broad categories of theoretical; expository (i.e. setting out an explanation of, or commentary on, the use of therapy); or research (descriptive, quantitative or qualitative), and to draw learning points from them in a narrative review.

## Results

### Psychotherapeutic Model

Of the 31 papers included in the review 17 could not be assigned to a model: they described: complex interventions (4 papers); non-specific interventions (7); or focused on other areas (methodology (2); ethics (1) and family

characteristics (3)). A total of 14 papers were assigned to a broad model: four to cognitive behavioral/ behavioral/psychoeducational (CBT); seven systemic; one mixed; and two psychoanalytic. The two psychoanalytic papers (Evans, 2004; Garner, 1997) focused on the application of psychoanalytic theory and understanding to later life contexts. The mixed model (Lévesque *et al.*, 2002) involved a group intervention, which appeared to combine elements of systemic therapy and CBT. Details of the eleven papers describing systemic therapy and CBT are set out in Table 1.

### **Narrative review**

Of the 31 papers identified, 5 were classified as theoretical; 11 as expository; and the remaining 15 as research (2 descriptive, 9 quantitative and 4 qualitative).

**Theoretical papers (n=5):** Two of the theoretical papers described methodologies. In one case the paper described methodology for developing complex interventions (Czaja *et al.*, 2003) and in the second the development of a research protocol (Joling *et al.*, 2008). The results of the research study carried out using the protocol were published in a paper included in the category of quantitative research (Joling *et al.*, 2012). The remaining three papers include some application to practice: two explore their topics through a predominantly psychoanalytic lens. Evans looks at a variety of theoretical approaches (including attachment theory) and uses illustrative case descriptions (Evans, 2004). She addresses domestic violence in the context of dementia; sexuality; loss by institutionalization; and death of a partner.

Garner focuses on intimacy, anticipatory grief and grief (Garner, 1997). She notes that apparently abnormal reactions of family members might be part of the process of coming to terms with the reality of a dementia in a close family member, and suggests that anticipatory grief might be a coping mechanism. Two important points Garner makes are that professionals need to acknowledge the meaning of dementia, its symptoms and losses for family members and that staff working in the area need to be skilled in providing psychological support. The fifth theoretical paper (Rolland and Williams, 2005) applies a family systems- illness model to genetic illness using Huntington's disease and early onset Alzheimer's disease as illustrative case examples. The authors write about the different phases, namely pre-genetic testing; the immediate testing period and post-genetic testing. It might be interesting to extrapolate their model to the period before, during and after memory clinic diagnosis of a dementia. They state that "we need a model that considers the unfolding of illness-related developmental tasks over the entire course of a disorder" (page 5). This paper overlaps with a paper classified as expository which addresses "the psychotherapy of genetics" (McDaniel, 2005).

**Expository papers (n=11):** Several of the expository papers do not describe family therapy but instead describe other psychotherapeutic interventions applied to family members, sometimes for clearly defined indications eg Koder used a cognitive behavioral approach to address anxiety amongst people with cognitive impairment (Koder, 1998). Qualls and Anderson make an important point in noting that the literature often focuses on family interventions aimed at carers, rather than what would be understood as family therapy per se (Qualls

and Anderson, 2009): the overlap between these two areas was evident in endeavoring to design a search strategy for this review. Qualls and Anderson specify particular techniques, which they regard as useful, including specific assessment techniques such as family interviews, genograms/ family trees, the observation of family conflict, and enactments (Qualls and Anderson, 2009). Other expository papers describe complex interventions, which involve family therapy alongside, or as part of, other interventions, eg Gallagher-Thompson and DeVries describe a psychoeducational/ cognitive behavioral intervention conducted with the relatives of people with dementia (Gallagher-Thompson and DeVries, 1994); Levesque et al describe group meetings for family carers which utilized some systemic techniques (notably reframing) (Lévesque *et al.*, 2002). Structural Ecosystems Therapy (SET) is described as an intervention: “to improve the caregiver’s interactions within her or his entire social ecosystem (family, community, health providers, etc.) to increase the extent to which the caregiver’s emotional, social and instrumental needs are met and, in turn, improve psychological adjustment” (Mitrani and Czaja, 2000). The model described combined systemic and ecosystem approaches and was delivered over a 12 month period: weekly for the first four months, then fortnightly for two months, and finally monthly for six months. The complexity of models employed in these papers makes it difficult to disentangle details of family therapy, and to assess its effect.

In terms of learning about practice, McDaniel makes a case for working with families involved in genetic testing (McDaniel, 2005); Peisah makes the case for family therapy as an adjunct to other dementia treatments (Peisah, 2006a);

Ugarriza and Gray argue that there is a role for family counseling in mid-stage dementia to help families manage the changes they are facing (Ugarriza and Gray, 1993); Wykle focuses on the potential role of family interventions in reducing carer stress (Wykle, 1996); and Qualls identifies transitions as times of particular difficulty/ opportunity (Qualls, 2000) (so for example when someone with dementia moves into institutional care, Qualls argues that family counseling might be beneficial).

Barber and Lyness write about ethical issues and their implications for family therapists (Barber and Lyness, 2001). They identify six ethical dilemmas: determining the extent of filial responsibility; equity in caregiving; competing commitments; balancing the care recipient's autonomy/ independence with safety/ well-being; knowing what the care recipient wants; financing care costs. They relate these to the ethical principles of respect for autonomy, beneficence, non-maleficence, and justice plus two others; truth-telling and filial obligation, and the authors argue that family therapists should explore ethical dilemmas with families they see, in order to help them in decision-making.

**Research papers 1 descriptive research (n=2):** Two papers were classed as descriptive research. One (Ginther *et al.*, 1993) examines individual, group and family counseling referrals for people with Alzheimer's disease in California, USA. Although the authors conducted logistic regression on their data, the value in terms of our review lies in the description of referrals to these three therapeutic modalities and why staff members were thought to

refer to each. Family counseling was regarded as appropriate to offer to families when the person with Alzheimer's disease deteriorated and in order to help families adjust to loss and the practicalities of caring. The authors note that pre-existing family conflicts may be exacerbated by increasing care needs, and that the aim of counseling was to help families continue caring. One interesting finding is that payment source was found to influence referral for counseling more than perceived need, but the importance of this factor will undoubtedly depend on the health system within which the family is living, although the influence of finances on care in many settings may be easy to underestimate.

The second descriptive paper is a UK based study of referrals of families where one member was living with a dementia to an old age psychiatry based family therapy clinic (Benbow *et al.*, 1993), comparing them with families attending the clinic for other reasons. The authors report that families coping with a dementia attended for fewer family meetings but that more family members attended, and that sons and daughters-in-law were more likely to attend. The paper refers to three possible roles for family therapy: as a primary agent of change; as a preliminary to accepting treatment; and as an adjunct to other treatments. An important point about evaluation of family therapy made here, is that outcome could be assessed from a number of perspectives, eg that of the referred person; that of the family as whole (or each family member separately); and from the perspective of the service or referring agent. In some of the research papers discussed below only the

perspective of carer/ family member is addressed and this may be a weakness of these studies.

**Research papers 2 Quantitative research (n=9):** Several papers focus on the effect of family interventions on carers' mood, particularly depression (Eisdorfer *et al.*, 2003; Joling *et al.*, 2012; Mittelman *et al.*, 2008) but also anxiety (Joling *et al.*, 2012). The effect of family therapy on carer burden has also been an area of investigation (Marriott *et al.*, 2000; Tremont *et al.*, 2006) as well as carer health/ well-being (Fisher and Lieberman, 1994; Mittelman *et al.*, 2007). One paper involves a complex intervention package but the role/ impact of family therapy cannot be separately identified (Kruglov, 2003): this study involved rating the impact of the intervention on people with dementia in terms of psychopathological symptoms and level of activity. A further paper reports the effectiveness of a support group for family carers rather than therapy (Fung and Chien, 2002).

Mittelman's seminal work with carers of people with dementia is well known. In 2007 she reported on a family intervention package, which involved six sessions of individual (two sessions) and family counseling (four sessions) over a period of four months, plus support group membership, plus ad hoc on-demand telephone counseling (Mittelman *et al.*, 2007). In 2009 she described a similar package, namely five sessions of individual (two sessions) and family counseling (three sessions - including at least one family member other than primary carer) in the first three months - this is referred to as the New York University (NYU) model - followed by ad hoc telephone on-demand

counseling (Mittelman *et al.*, 2008). The therapy is described as involving education and information as well as help in understanding behavior.

Mittelman's work looked at carers' self-rated physical health/ numbers of illnesses (Mittelman *et al.*, 2007); and depressive symptoms (Mittelman *et al.*, 2008); and also suggests that family intervention can delay nursing home placement, especially in the early to middle stages of Alzheimer's disease (Mittelman *et al.*, 1996; Mittelman *et al.*, 2006).

**Research papers 3 Qualitative research (n=4):** The use of couples therapy has been described for couples including one partner with early Alzheimer's disease, with its purpose being "to preserve the integrity of the relationship and the sense of self of each partner when one of them is diagnosed with Alzheimer's disease" (Auclair *et al.*, 2009) (page 131). The approach underpinning the counseling is described as "looking at the members of a couple as equal players in the marital drama (which) offers an affirming view of their relationship and its capacity to embrace change" (Auclair *et al.*, 2009)(page 132). The authors offer a series of vignettes as qualitative evidence of the value of the approach, which involved six couple therapy sessions within a two-month period.

Sobel and Cowan interviewed family members who had undertaken DNA testing for Huntington's disease and conclude there is a role for family therapists to help families deal with the subsequent loss and grief (Sobel and Cowan, 2003). A third qualitative paper involves interviews with counselors who had delivered the NYU family intervention (Vernooij-Dassen *et al.*, 2010).

Family problems (and ways of dealing with them) were identified as major themes and include family conflicts; the influence of personality and past experience; and living with dementia. Barriers encountered by counselors (and ways of dealing with them) are further themes and include reluctance to be helped, but the counselors involved regard the rewards of helping the families as outweighing these barriers. Garwick, Detzner and Boss describe the qualitative analysis of family interviews of families with a member with early Alzheimer's disease (Garwick *et al.*, 1994). They report that the families involved in the project **feedback** how beneficial they had found talking as a family and the authors recommend that a family meeting should be held at the time of diagnosis of Alzheimer's disease, observing that "new meanings and interpretations" often emerged during the discussions. They note that families may exclude a member (not always the person with dementia), because of denial of the disease or the person's cognitive impairment or disagreements about roles and responsibilities, and that this could be a reason for family intervention. They also comment on families' needs to redefine tasks and responsibilities; to adjust to grief and loss; and to adapt family rituals (eg those associated with celebrations) in order to continue to include the person with cognitive impairment.

## **Discussion**

Much of the literature, which purports to focus on family therapy/ counseling and dementia, in fact focuses on the main carer, uses some techniques drawn from family therapy, or includes family therapy as part of a complex

intervention package. Those papers, which employ therapy/ counseling, often only give a brief broad indication of the model or approach utilized. The two main models of therapy identified in the review were systemic therapy and CBT. CBT was primarily used to target specific symptoms; including anxiety in people with cognitive impairment and anxiety/ depressive symptoms in carers. Much of the systemic literature identified rests on description or case studies. Part of the underlying problem is that research remains linear, rather than systemic, in its focus, and investigates outcomes for the patient or carer rather than looking at changes in the system in which they are embedded. This linear research perspective may be influenced and organised by a narrow understanding of dementia as due to organic disease and associated with the aging process. This understanding may create ambiguities especially when dementia affects younger people: dementia does not discriminate on the grounds of age, gender, class and culture. A systemic perspective requires consideration of how we talk about dementia, the language we use and the questions we ask the person living with dementia, their carer and family members.

Future research would benefit from clarity regarding the therapeutic model employed and its application in practice; evaluation of both family and patient outcomes; and evaluation of broader change within the system. Endeavoring to investigate systemic outcomes will necessitate a way of evaluating collaboration, the mutual exchange of ideas/ views between family members and health and social care staff members, and the mutual construction of outcomes which may be different from the ones originally anticipated

(Benbow, 2012). In this way a systemic perspective on the problem determining and dis-solving system (Anderson and Goolishian, 1996) would open up multiple perspectives, truths and realities in how we understand 'dementia', and its 'management'.

Our review identified papers which used a variety of outcome measures, including carers' mood (depression or anxiety); carers' health/ well-being; carers' burden; and nursing home placement. Martire and colleagues (Martire *et al.*, 2004) carried out a meta-analysis of psychosocial interventions ("interventions that involved a family member" page 600) for chronic illness, which included dementia, and note that goals might be to improve the health and/or well being of person with dementia, family member, or both. They found that the strongest evidence for efficacy of family interventions (as defined by them) was in relation to family burden: family interventions reduced the caregiving burden of those family members caring for people with dementia. It also appears that such interventions led to the closest family member feeling less depressed and burdened; and family members' anxiety is reduced when a focus on relationship issues between person with dementia and carer was included in therapy. Depression amongst people with dementia is only reduced when the work focuses on couples.

Thus evaluation of therapy is complex. One complication in evaluating outcomes is that of biased aims, eg if the aim is specified as being to support family carers to carry on caring (Ginther *et al.*, 1993) then a decision for the person with dementia to move into a care setting would constitute a "failure" of

treatment; but who is to say that is not the best decision for the family and individual involved? Treatments aimed at benefiting families should logically be evaluated from a variety of perspectives, including that of the person living with dementia and the referring agent (if one is involved). This might also be a useful principle to apply in routine practice. Marriott and colleagues focused their cognitive-behavioral family intervention on the carer, aiming to reduce carer stress and distress (Marriott *et al.*, 2000), but they hypothesize that improvement in carers' management skills would lead to an improvement in outcomes for people with dementia. Similarly Fisher and Lieberman argue that programs should focus on the multi-generational family rather than just the caregiver, since dementia impacts on the whole family (Fisher and Lieberman, 1994). Family therapists work to promote family members' resilience in terms of their practical, psychological and emotional responses to illness and later life issues. The focus may be on decision-making, dilemmas of care provision at different stages of dementia, and re-structuring of family functioning: for example deciding the type of care needed, who the primary carer might be, available resources and social networks.

Evaluation should be underscored by attention to what is being measured and why. Who decides whether a particular outcome is positive? If different people rate outcomes differently, this needs to be acknowledged rather than privileging one particular perspective or one preferred outcome. Assessing outcomes from multiple perspectives appears to make sense, but the differing perspectives and aims of the various stakeholders will complicate any conclusions that might be drawn.

Many family therapy outcome measures have been developed and are supported by published literature, but have not been adapted for or evaluated with later life families: this is probably not surprising as family therapy developed in response to families presenting with difficulties in childhood and adolescence (Dallos and Draper, 2010). One example of a tool is the SCORE-15 Index of Family Functioning and Change (Stratton, 2014), a freely available self-report tool which has been developed in the UK with the support of the Association for Family Therapy and Systemic Practice. Some of these tools have been available for a number of years, for example the ENRICH (Evaluation and Nurturing Relationship Issues, Communication and Happiness) Marital Satisfaction Scale (Fowers and Olson, 1993). The application and/ or modification of existing tools to work with later life families is an area for future research.

### ***Challenges for family therapy and dementia***

The challenges for family therapy in relation to families living with dementia can be divided into the context; the family; and the therapy.

The health and social care context offers challenges in terms of making family therapy available to families. Depending on the care system, therapy may have to be paid for (Peisah, 2006b). If this is the case, the question of payment may influence whether therapy is even suggested as an option (Ginther *et al.*, 1993) and family finances may be a barrier to treatment. In

some systems, therapy for specified conditions may be publicly funded (eg the IAPT program was initially aimed at people with anxiety and depression and made available as part of the NHS) but this may involve limiting the number of sessions paid for from public funds.

In the United Kingdom (UK) there are very few NHS family therapy positions working with older adults and their families compared with child and adult services. The paucity of clinicians working in older people's mental health services who are trained in systemic formulation and the use of family therapy is a barrier in making therapy available more widely. Those who are trained in family therapy are often social workers, and family therapy for older people is rarely part of the family therapy training curriculum in any discipline. Our current definition of dementia may constrain how people live with and manage dementia: it influences what we believe about the condition, how to be a 'good dementia patient' and how to be a 'good carer', instead of supporting families to find ways of living well with dementia. It may also account for the distribution of the trained workforce in the treatment and management of dementia.

Current trends towards increased home-based health and care provision suggest that health and social care professionals working with families living with dementia need to acknowledge and reach out to voluntary groups as core care providers. Promoting access to family therapy at local community level requires recognition of the differences of approach between medical healthcare, mental healthcare and social care professionals and an

understanding of psychological interventions for long-term illnesses. The approach, method and technique of working with voluntary sector groups introduces a new definition of relational help for a relational problem (Burnham, 1992). Making systemic family therapy available and accessible at local community level requires flexibility and is about thinking on, in and out of the box (Child, 2013). Family therapists working in mixed sectors, outside the NHS, are bringing specialism and generalism closer together, and widening the scope of family therapy work to meet people's needs in both statutory and voluntary sectors (Child, 2012). Increased availability of therapy for families living with a dementia requires the development of theoretical frameworks including ethical consideration in working with private and voluntary sectors and the need to build collaborations across sectors. Medical and technological advances in health and care provision offer further opportunities and/ or challenges, e.g. there is increasing interest in the use of the Internet in therapy provision.

In many areas there is a need for knowledge and skills in working with multiple languages, cultural beliefs and values (Dementia Plus, 2001). Dilworth-Anderson and Gibson found that cultural beliefs and values influence the perception of illness and can determine the method of treatment (Dilworth-Anderson and Gibson, 2002). There is a need for research on living with dementia among black and minority groups as this population is forecast to increase and there has been a lack of study in this field in the UK (Bhattacharyya and Benbow, 2013; Lampley-Dallas, 2002; Milne and Chryssanthopoulou, 2005).

The second area of challenge relates to families. Families come in different shapes and sizes, which can complicate the practicalities of family therapy. In setting up a family meeting who should be invited and how are they to be engaged in the work (Qualls, 2000)? A series of sessions may be attended by different family members: in the report of York House Family Clinic the maximum number of family members present in a session was eight (Benbow *et al.*, 1993) and one of us (SMB) has been involved in sessions involving up to eleven family members. This complexity complicates the family meeting and assessment of outcomes: some family members may report benefit and not others – what constitutes success and who decides whether therapy is a success? In this context perhaps it is not surprising that research has been undertaken predominantly with the primary caregiver.

Confidentiality issues may be a concern in bringing family members together (Peisah, 2006b), for members of the family and/or for therapists. Family members may not wish to share some thoughts, fears or events from the past with other family members. Carers may be reluctant to talk freely in front of the person with dementia. The person with dementia may not wish to share fears that might distress or worry their relatives. These concerns are not unique to therapy and may be greater for those professionals who are not used to talking with family groups.

The third area of challenge relates to the therapy itself. One of the challenges for any therapy is ensuring treatment integrity, i.e. consistency in the

treatment intervention, particularly when it moves from research to become more widely available in practice (Czaja *et al.*, 2003), and, given the diverse nature of family members, families and therapists, including variation in who is involved in therapy, this is a notable challenge (Qualls, 2000). Psychological treatments need to be flexible but underpinned by a clear model and approach (Martire *et al.*, 2004). It is possible that specific family interventions or approaches are more useful or more suited to some family situations rather than others, although the literature is limited and does not support firm conclusions regarding the approach of choice: systemic therapy works with the family as a system, and logic suggests that it might be more appropriate for complex family dilemmas. In dementia care settings the content of family meetings may be a challenge. Loss (actual or anticipated), grief, and the difficulty of living with uncertainty are common emotions for those living with dementia (Garner, 2003; Sobel and Cowan, 2003): “all the bereaved continue to relate to one another, and, in so doing, their experiences of grief inevitably are influenced, and in turn influence the experiences of the relatives” (Kissane and Bloch, 1994) p 737. The diagnostic language of dementia constrains theories of experiencing and living with dementia. A systemic perspective focuses on the lived experience of people and their families, and the meaning it holds for them. The value placed on short-term memory, with implied loss of intellectual ability/power, and how its loss is construed and explained may exert a strong influence on the emotional expression and participation of people living with dementia.

***Guidelines available to guide family therapists***

The Leeds Family Therapy and Research Centre has published a Systemic Family Therapy Manual (Pote *et al.*, n/d; Pote *et al.*, 2003) which was designed as a research tool, but could also offer guidelines for therapists working with families living with dementia and a framework for ensuring consistency in delivery of therapy. There is also a resource book offering practical details of the NYU family intervention program, which contains information on assessment and intervention planning (Mittelman *et al.*, 2002).

### ***Roles for family therapy and dementia***

Four roles have been suggested for therapy in relation to families living with a dementia and they are considered in turn below.

Firstly, therapy may act as an agent of change. In the context of dementia perhaps this might also include therapy as offering a forum for making decisions about change. One-off family conferences can help families to come together and make difficult decisions.

Although the role for family therapy as a primary agent of change may be limited, apart from in families where grief or long standing relationship conflict is the focus, family therapy may be a useful way of supporting families in making major decisions. This is similar to the second role for therapy, namely as a preliminary to the acceptance of treatment. Benbow and colleagues reported that families living with dementia more often attended the family clinic once, to resolve a crisis, and that this might be regarded as employing

therapy as a preliminary to the acceptance of treatment in its widest sense, including social and environmental aspects of treatment (Benbow *et al.*, 1993), and as a way of bringing family members together in order to agree future plans. An interesting study by Peisah, Brodaty and Quadrio involved a qualitative analysis of the file notes of fifty cases of family/ systems conflict involving a person with dementia presented to the Guardianship Tribunal in New South Wales, Australia. The authors noted that family therapy had not been employed prior to application to the Tribunal and argued the case for making available interventions to address “family dysfunction” in medico-legal cases (Peisah *et al.*, 2006).

A third role, namely therapy as an adjunct to other treatments, seems to be one of the ways in which Peisah employs family therapy (Peisah, 2006b). Two of her case examples involve someone living with dementia. In one case example the problem is management of behavioral and psychological symptoms of dementia (BPSD) in institutional care, and, in a second, therapy took place with the two daughters of a woman with dementia living in the community.

The fourth and final role is as a source of techniques, which can be applied in other areas of practice. Peisah notes the importance of using family therapy techniques in this way, as distinct from as part of formal therapy. She highlights four specific techniques as being useful: genograms/ family trees as part of information gathering (also mentioned by Quall and Anderson (Qualls and Anderson, 2009)); an understanding of the family life cycle/ spiral;

positive reframing (also used by Lévesque and colleagues (Lévesque *et al.*, 2002)); and asking family members to describe what has been tried in response to problems and found not to work (thus highlighting actions/responses that might be maintaining a particular behavior).

Figure 1 draws these roles together into a pyramid of three tiers, requiring increasing levels of family therapy knowledge and training. The bottom tier (Tier 1) involves using family therapy techniques in everyday practice in health and social care. For example genograms are used by family therapists but could be incorporated routinely into psychiatric, general practice and social work histories and assessments, thereby adding to understanding of families as well as recording family information in a succinct and useful manner. Tier 2 involves the use of family therapy alongside other treatments in a supportive/ adjunctive role. This would involve workers who have undertaken some training in therapy. Tier 3 involves more specialist family therapists offering formal family meetings, which are the focus of decisions/change and relational support. Individual family therapists may contribute across tiers eg using systemic family therapy techniques in community projects or teaching them to community workers in tier 1; offering family therapy as an adjunct to other treatments in general practice in tier 2; and providing specialist therapy in independent practice in tier 3.

## **Conclusions**

The literature on family therapy and dementia has grown over the past 25 years but remains limited and any conclusions we might draw are modest. Nevertheless this review suggests that therapy could have a number of useful roles in dementia care. Therapy as a preliminary to accepting other treatments encapsulates the potential role of family therapy in bringing family members living with dementia together to recognize their own and each other's roles, support one another, resolve conflicts related to the dementia, and negotiate and agree a holistic treatment plan. Some of the literature we reviewed targets specific symptoms in family members in response to therapy, but there is a need for further research which looks more broadly at changes in the family system, at the relationship between the family and health/social care, and in individual members of the family system. Areas to explore include: how to evaluate the success of therapy; how to ensure treatment integrity; how to make systemic family therapy perspectives and techniques available more widely; and how to train the health and social care workforce in working with families. A tiered model might facilitate the application of therapy to practice.

Widening access to family therapy will necessitate clear goals against which to evaluate its success, and clarity regarding useful therapeutic models. The NYU Caregiver Intervention program set as its goals: "to maintain the well-being of the primary caregiver and (to) reduce premature or unwanted nursing home placement of the person with dementia" (Vernooij-Dassen *et al.*, 2010) page 776. Perhaps future research could also address goals of maintaining the well-being of the person with dementia and reducing the burden of family

members as suggested by Martire and colleagues (Martire *et al.*, 2004).

These are useful goals to incorporate more widely into routine dementia care.

### **Conflicts of interest declaration**

This review was unfunded.

Susan Mary Benbow practices as an independent systemic therapist, and  
Victoria Sharman as a systemic family psychotherapist

### **Description of authors' roles**

Susan Mary Benbow designed the study, formulated the aims, carried out the search and wrote the paper. Victoria Sharman read the papers, assisted in identifying the learning points and contributed to writing the paper.

prepublication draft

Table 1: Systemic therapy and CBT papers identified in the literature search

Paper	Details of therapy	Number of sessions	Target group	Type of paper
<b>Systemic therapy (n=7)</b>				
Benbow <i>et al.</i> , 1993	Systemic therapy involving techniques including positive reframing, circular questioning, genograms etc.	Varied: mean 1.6 sessions/ family.	Families living with dementia.	Research - descriptive
Eisdorfer <i>et al.</i> , 2003	Structural ecosystems therapy with or without technological intervention.	Weekly for 4 months, then biweekly for 2 months, then monthly for 6 months.	Family carers (depressive symptoms).	Research - quantitative
Mitrani and Czaja, 2000	Structural ecosystems therapy.	As above	Family carers (case examples)	Expository

			described).	
Peisah, 2006	“Application of concepts from family and systems theory” page 346.	Varied.	Old age psychiatry practice (case examples described).	Expository
Qualls, 2000	“Family therapy attempts to alter either a system’s functional approach to accomplishing a task or the structural configuration ... within which the family operates for the purpose of improving functioning.” Page 192.	n/a	Families.	Expository
Qualls and Anderson, 2009	“grounded in systems theory” page 846.	n/a	Carers.	Expository
Rolland and Williams, 2005	Family systems-illness model “developed to provide a framework	n/a	Chronic illness and disability including	Theoretical

	for psychoeducation, assessment, and intervention” page 5.		dementias.	
<b>Cognitive behavioral therapy (n=4)</b>				
Gallagher-Thompson and DeVries, 1994	Psychoeducational intervention aimed at frustration and anger.	Eight group classes followed by two booster sessions.	Women caring for people with dementia	Expository
Joling <i>et al.</i> , 2012	“Psycho-education, teach problem solving techniques and mobilize the existing family networks ... in order to improve emotional and instrumental support.” Page 2.	Two individual and four family meetings.	Family carers (anxiety and depressive symptoms).	Research - quantitative
Koder, 1998	CBT	Two case descriptions	Anxiety symptoms in people with cognitive impairment	Expository

Marriott <i>et al.</i> , 2000	Individual therapy with carers from a family therapy (cognitive behavioral) perspective, involving carer education, stress management and coping skills training.	“Lengthy”.	Patient-carer dyads (carer distress and depression).	Research - quantitative
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**Table 2: Papers identified in the literature search with broad classification and comments**

Authors/ year	Title	Comments
<b>Theoretical papers (n=5)</b>		
Czaja <i>et al.</i> , 2003	A methodology for describing and decomposing complex psychosocial and behavioral interventions.	Not relevant.
Evans, 2004	Sex and death: The ramifications of illness and aging in older couple relationships.	Mentions domestic violence in the context of dementia and loss by institutionalization. Mainly psychoanalytic perspective.
Garner, 1997	Dementia: an intimate death.	Focus on intimacy and anticipatory grief – psychoanalytic perspective.
Joling <i>et al.</i> , 2008	(Cost)-effectiveness of family meetings on indicated prevention of anxiety and depressive symptoms and disorders of primary family caregivers of patients	Description of study protocol. The study is reported in Joling et al, 2012.

	with dementia: design of a randomized controlled trial.	
Rolland and Williams, 2005	Toward a bio psychosocial model for 21st-century genetics.	Applies a family systems- illness model to genetic illness. Uses Huntington's and early onset Alzheimer's disease as illustrations.
<b>Expository papers (n=11)</b>		
Barber CE and Lyness, 2001	Ethical issues in family care of older persons with dementia: implications for family therapists.	Perspective of contextual family therapy. Addressed at family therapists.
Gallagher-Thompson and DeVries, 1994	"Coping with frustration" classes: development and preliminary outcomes with women who care for relatives with dementia.	Psychoeducational/ cognitive behavioral intervention with relatives of people with dementia.
Koder, 1998	Treatment of anxiety in the cognitively impaired elderly: can cognitive-behavior therapy help?	Describes use of cognitive behavioral techniques to treat anxiety in people with cognitive impairment.
Lévesque <i>et al.</i> , 2002	The process of a group intervention for caregivers	Describes group meetings for family carers which utilized some systemic

	of demented persons living at home: conceptual framework, components, and characteristics.	techniques.
McDaniel, 2005	The psychotherapy of genetics.	Describes a role for working with families involved in genetic testing (for Huntington's disease and genetic forms of Alzheimer's).
Mitrani and Czaja, 2000	Family-based therapy for dementia caregivers: clinical observations	Describes Structural Ecosystems Therapy (SET), which addresses the needs of family in a joint context, and aims to transform family relationships as a means of improving caregiver support.
Peisah, 2006	Practical application of family and systems theory in old age psychiatry: Three case reports.	Two case histories relevant to dementia. Focus on family therapy as an adjunct to treatment.
Qualls, 2000	Therapy with aging families: Rationale, opportunities and challenges.	Identifies transitions as times of particular difficulty. Case example of person with cognitive impairment.

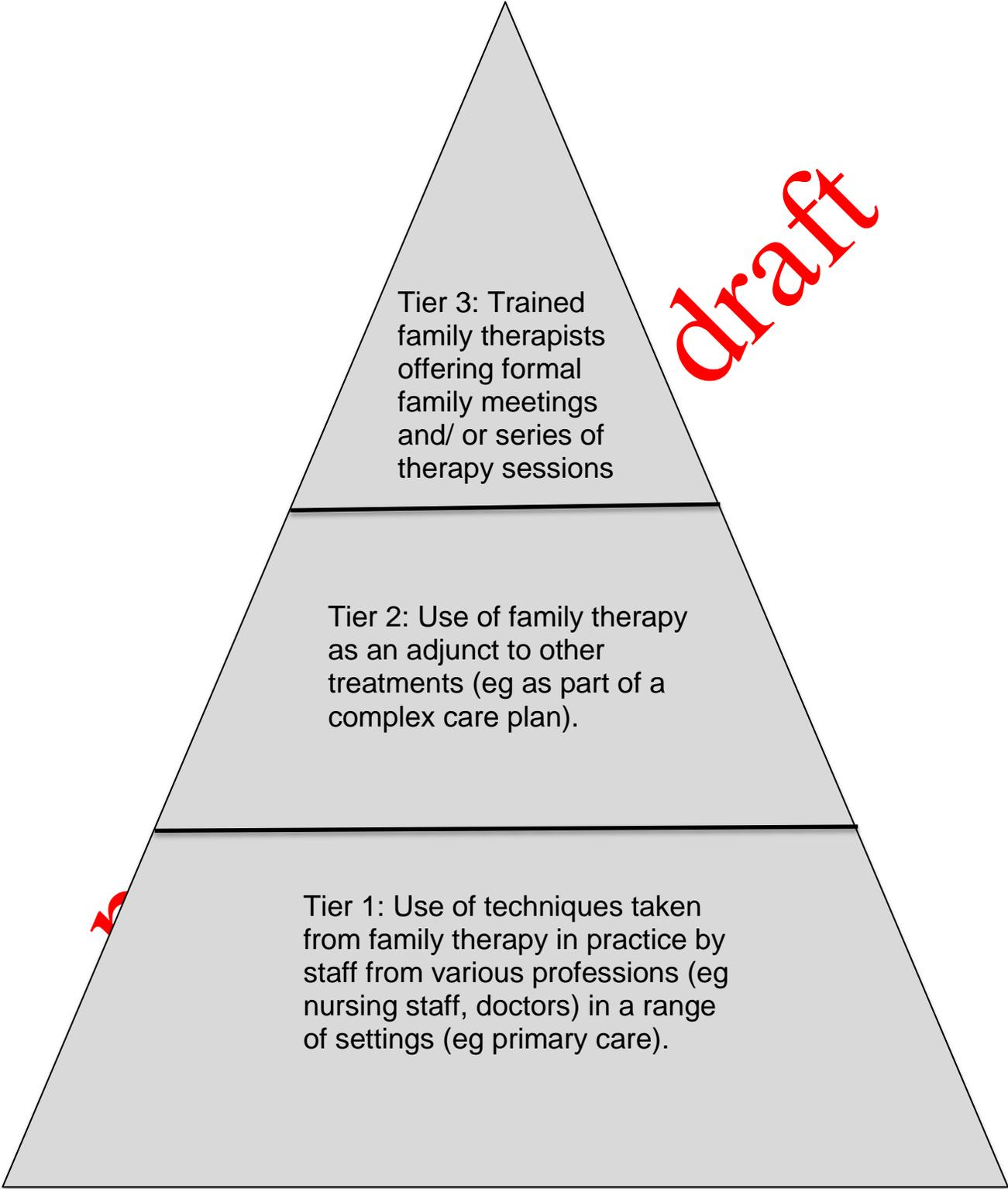
Qualls and Anderson, 2009	Family therapy in late life.	Notes that research often focuses on family interventions aimed at carers.
Ugarriza and Gray, 1993	Alzheimer's disease: nursing interventions for clients and caretakers.	Describes a role for counseling to assist in family management in mid-stage dementia
Wykle, 1996	Interventions for family management of patients with Alzheimer's disease.	Focus on how family interventions might help carers by reducing stress.
<b>Research – descriptive (n=2)</b>		
Benbow <i>et al.</i> , 1993	Family therapy and dementia: review and clinical experience.	Retrospective case note study of 33 families seen in a family therapy clinic.
Ginther <i>et al.</i> , 1993	Professional allocations of counseling service to persons with Alzheimer's disease: an exploration	Describes individual, group and family counseling referrals for people with Alzheimer's disease.
<b>Research – quantitative (n=9)</b>		
Eisdorfer <i>et al.</i> , 2003	The effect of a family therapy and technology-based intervention on caregiver depression.	Uses a form of brief strategic family therapy and technology to allow distant family members to take part. Focuses on reduced depressive symptoms in carers.

Fisher and Lieberman, 1994	Alzheimer's disease: the impact of the family on spouses, offspring, and in-laws.	Investigated family characteristics related to health and well-being of family carers.
Fung and Chien, 2002	The effectiveness of a mutual support group for family caregivers of a relative with dementia.	Evaluated a support group for family carers.
Joling <i>et al.</i> , 2012	Does a Family Meetings Intervention Prevent Depression and Anxiety in Family Caregivers of Dementia Patients? A Randomized Trial	Randomized multi-centre trial of two individual sessions and four family meetings conducted once every 2-3 months for 12 months. Focus on depression and anxiety amongst carers.
Kruglov, 2003	The early stage of vascular dementia: significance of a complete therapeutic program.	Involves a complex intervention package, which includes family therapy. Role/ effect of family therapy cannot be separately identified.
Marriott <i>et al.</i> , 2000	Effectiveness of cognitive-behavioral family intervention in reducing the burden of care in carers of patients	Individual therapy with carers from a family therapy (cognitive behavioral) perspective. Argues that therapy should improve outcomes for both people with dementia and carers.

	with Alzheimer's disease.	
Mittelman <i>et al.</i> , 2007	Preserving health of Alzheimer caregivers: impact of a spouse caregiver intervention.	Intervention involved 2 sessions of individual and 4 sessions of family counseling plus ad hoc on-demand telephone counseling. Self-rated health's of carers significantly different for 2 year follow up.
Mittelman <i>et al.</i> , 2008	A three-country randomized controlled trial of a psychosocial intervention for caregivers combined with pharmacological treatment for patients with Alzheimer disease: effects on caregiver depression.	Intervention involved 2 sessions of individual and 3 sessions of family counseling followed by ad hoc on-demand telephone counseling. Carer depression scores decreased over time.
Tremont, Davis and Bishop, 2006	Unique contribution of family functioning in caregivers of patients with mild to moderate dementia.	Used a variety of standardized scales with live-in family carers of people with dementia. Suggest that family therapy has a role in preventing carer burden.
<b>Research – qualitative (n=4)</b>		

<p>Auclair, Epstein and Mittelman, 2009</p>	<p>Couples Counseling in Alzheimer's Disease: Additional Clinical Findings from a Novel Intervention Study.</p>	<p>Describes couples counseling for couples one of whom has early Alzheimer's disease. Includes case vignettes.</p>
<p>Garwick, Detzner and Boss, 1994</p>	<p>Family perceptions of living with Alzheimer's disease.</p>	<p>Qualitative analysis of interviews with multigenerational families living with a member who has early Alzheimer's disease.</p>
<p>Sobel and Cowan, 2003</p>	<p>Ambiguous loss and disenfranchised grief: the impact of DNA predictive testing on the family as a system.</p>	<p>Describes a role for therapists in helping families deal with loss and grief after DNA testing for Huntington's disease.</p>
<p>Vernooij- Dassen <i>et al.</i>, 2010</p>	<p>The process of family- centered counseling for caregivers of persons with dementia: barriers, facilitators and benefits.</p>	<p>6 sessions of individual/ family counseling plus support group plus on- demand telephone counseling. Reports interviews with counselors.</p>

Figure 1: Pyramidal model of family therapy in dementia practice



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