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# Services to Support Carers of People with Mental Health Problems

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***Literature Review Report  
for the  
National Co-ordinating Centre for NHS Service  
Delivery and Organisation R & D (NCCSDO)***

***Summer 2002***

*prepared by*

Hilary Arksey, Lisa O'Malley, Sally Baldwin and Jennifer Harris  
Social Policy Research Unit, University of York

Anne Mason  
Centre for Health Economics, University of York

*Searches:*  
Su Golder  
NHS Centre for Reviews and Dissemination, University of York

Address for correspondence:

Dr Hilary Arksey, Research Fellow  
Social Policy Research Unit  
University of York  
Heslington  
York YO10 5DD

Email: [ha4@york.ac.uk](mailto:ha4@york.ac.uk)  
Telephone: 01904 432626  
Fax: 01904 433618

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## **Executive Summary**

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### **Background**

Mental ill health is very common in the UK; at any one time, around one in six people of working age suffer from one or other form of mental illness. As far as older people are concerned, around 10–15 per cent of the population (65 and over) will have depression, and around 600,000 will have dementia. Family and friends support up to half of those with severe mental illness. Up to 1,500,000 people may be involved in caring for a relative or friend with a mental illness or some form of dementia. The needs of those caring for people with mental illness or dementia are high, and recent government policy has recognised the key role that carers play. For example, the National Service Frameworks for Mental Health and Older People put a high priority on meeting the practical, health and emotional needs of this particular group of carers.

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### **Objectives**

The aim of this report is to provide a scoping review of evaluation studies of interventions and services to support carers of people with mental health problems, to discuss issues relating to the effectiveness and cost-effectiveness of interventions, and to provide insights into areas where there are gaps in knowledge. The report is accompanied by a second report, the *Consultation Report*, that documents a consultation exercise held with key stakeholders, including 'key informant' carers. A third report, the *Overview Report*, draws together the emerging themes and issues, and advises on what further research and development work should be funded in this area.

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### **Methods**

#### ***Data sources***

Searches were made of electronic databases, including: AMED, ASSI, BNI, Cinahl, Cochrane Library, EMBASE, HMIC (King's Fund Database, HELMIS, Dhdata), Medline, SIGLE, Social Science Citation Index, Sociological Abstracts.

Internet resources used included: Caredata, Database of Abstracts of Reviews of Effectiveness (DARE), Health Technology Assessment Database (HTA), the NHS Economic Evaluations Database (NHS EED).



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All sources were searched for studies published between 1985 and 2001. Other search strategies included hand searching, searching websites of key organisations (for example, the Department of Health, National Schizophrenia Fellowship, Alzheimer's Society, Carers UK, The Princess Royal Trust for Carers), and contacting librarians of organisations such as the Sainsbury Centre for Mental Health and the Mental Health Foundation. Bibliographies of studies were checked to ensure referenced studies were included.

### ***Study selection***

Research reports were selected if they were empirical studies that addressed the research question: What is known from the existing literature about the effectiveness and cost-effectiveness of services to support carers of people with mental health problems?

Specific inclusion criteria were:

- *intervention type*: any intervention directed towards carers of people with mental health problems, including dementia
- *care recipient group*: any care recipient group comprising individuals 18 years of age and over with any mental health problem
- *carer group*: carers of any age. Carers of people with mental health problems
- *study aims*: studies that have evaluated the effectiveness or cost-effectiveness of services to support carers of people with mental health problems.

Studies that were not empirical and not in English were excluded; so, too, were book reviews, commentaries and PhD theses.

Two reviewers identified studies by screening study titles and abstracts, and then by examining the full text of selected studies to decide inclusion. The initial search generated 3867 references; 204 of these were included in the scoping review, 13 of which included an economic evaluation.

### ***Data extraction and synthesis***

If reported, the following data were extracted from each paper:

- intervention type and comparator (if any)
- study sample
- care recipient group
- aims of study
- research methods
- duration of the intervention
- outcomes
- country where the study was set.

Further data extracted only from the economic evaluations included:

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- types of costs included
- whether cost data were collected retrospectively or prospectively
- currency used to report findings
- measures of benefits reported
- whether there was a synthesis of costs and benefits.

A narrative synthesis of the data was conducted which included descriptive characteristics, as well as more substantive issues such as effectiveness and cost-effectiveness. Gaps in the research were also identified.

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## **Results**

### ***Mapping the results***

#### **Geographical distribution**

The majority of studies were carried out in the USA (55 per cent). Some 22 per cent of reports derived from the UK. Canada and Australia each accounted for 7 per cent of the studies. Studies from the rest of Europe and the rest of the world accounted for the remainder.

#### **Care recipient group**

The majority of interventions were aimed at carers of people with Alzheimer's disease (AD) or other dementia (70 per cent). The rest were split evenly between carers of people with schizophrenia (15 per cent) and carers of people with other serious mental illness (15 per cent). Most of the studies focusing on carers of people with AD or dementia were carried out in the USA (44 per cent).

#### **Type of intervention**

The 204 studies included in the review were diverse and complex. The classification scheme developed consisted of 11 different groups of interventions relevant to current policy and the aims of the study:

- 1 educational interventions of different types (36 per cent)
- 2 breaks from caring (18 per cent)
- 3 family interventions (10 per cent)
- 4 mutual support and social activity groups (9 per cent)
- 5 telephone and computer-based services (8 per cent)
- 6 multidimensional approaches to caring interventions (7 per cent)
- 7 counselling (4 per cent)
- 8 domiciliary care services (2 per cent)
- 9 physical environment (1 per cent)

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- 10 supporting carers through memory clinics (1 per cent)
- 11 miscellaneous (4 per cent).

### **UK studies**

Of the 44 studies set in the UK, 18 targeted AD/dementia patients, 14 targeted people with schizophrenia, and the remaining 12 were for carers of people with other serious mental illness. No study focusing on acute or chronic depression, eating disorders, anxiety or substance abuse was identified, although some people with depression or anxiety were among the participants in a small number of studies. The majority of studies described interventions aimed at the family (13). Educational interventions and breaks from caring accounted for 11 and 8 studies respectively.

### **Research methods**

Some 80 per cent of studies adopted quantitative methods. Of these, randomised controlled trials (RCTs) accounted for 33 per cent of studies, non-randomised controlled trials for 20 per cent, before-and-after studies (uncontrolled) for 31 per cent, and post-intervention measures for 16 per cent. The remaining 20 per cent of studies used mainly mixed methods or qualitative methods. Most studies were experimental or quasi-experimental. Just over one-quarter of studies included follow-up at three months or over; longer-term follow-up was rare.

### **Measures of effectiveness and cost-effectiveness**

Seventy per cent of all the studies included in the review used standard outcome measures as a way to assess the effectiveness of interventions. Carer burden, stress, coping, physical health, emotional well-being, depression and knowledge levels were commonly measured. Alternative or additional ways to assess the effectiveness of interventions included programme evaluation surveys, satisfaction surveys, service utilisation rates, relapse rates and admissions to institutional care or hospital. Most of the studies with an economic component include health care costs and social services costs. Only one study valued carer time, while two assessed changes in carer earnings.

### ***Effectiveness and cost-effectiveness***

The analysis of studies of interventions for carers of people with mental health problems found the following in relation to effectiveness and cost-effectiveness.

- Overall, there was a lack of clear evidence to support any specific interventions for carers for people with mental health problems, although almost all studies were able to identify some positive outcomes of services provided.

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- The analysis highlighted recurrent methodological weaknesses in the studies under review: small sample sizes, problems with attrition, problems relating to the use of control groups, and inadequate follow-up.
- Studies generally reported modest effects on carer burden and quality of life, with some evidence that the provision of publicly funded services led to a proportionate decrease in privately funded services.
- Some studies provided tentative evidence that offering carers respite breaks may actually increase the rate of patient institutionalisation. However, further research is required to verify this finding.
- There was some evidence that assertive outreach for patients with severe mental illness is at least as effective as standard inpatient care, and that this could also be cost-effective.
- Cost savings were reported for a range of interventions, resulting from decreased use of hospital-based care. However, there were methodological weaknesses in all studies with this conclusion.
- The provision of educational materials for carers improves carer knowledge, but may not reduce carer burden. Training interventions take many forms and positive effects are reported for certain types of training. Evidence regarding the effectiveness of psychoeducational approaches for carers is diverse and contradictory.
- Overall, there was a lack of clear evidence to support any specific interventions for carers for people with mental health problems, although almost all studies were able to identify some positive outcomes of services provided.

## ***Gaps in the research***

The analysis identified the following key gaps in the literature:

- studies examining the effectiveness of interventions in relation to different sub-groups of carers, including: children and young adult carers; black and ethnic minority carers; spouse carers; male carers and female carers; working and non-working carers; carers of different patient groups
- studies evaluating interventions for carers of patients with acute or chronic severe depression; severe eating, anxiety or sleep disorders; substance abuse
- research into the effectiveness of interventions promoted in current policy, in particular: carer assessment; care plans; comprehensive packages of care; breaks from caring; family support; the use of telephone help-lines and computer-based interventions
- studies to determine which, and what combination of, elements in a multidimensional package are effective and cost-effective and for whom
- research looking at the relationship between the different stages of an illness and specific interventions
- studies measuring key process outcome measures, relating to the structure, delivery and organisation of services

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- research examining the effectiveness and transferability of interventions currently targeted at only one specific patient group
- research designs that use qualitative and mixed or multiple methods
- studies assessing the effectiveness of interventions other than through the use of standard outcome measures
- studies powered to detect statistically significant differences in both effectiveness and cost-effectiveness measures
- longitudinal studies, to examine effectiveness and cost-effectiveness in the short and longer term
- innovative approaches to developing, implementing and assessing interventions which draw on carers' own particular expertise.

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## **Recommendations for research**

Future research should take into account the points just made.

Recommendations for future research and development are provided in the accompanying *Overview Report*, which draws together issues arising from both the literature review and the consultation exercise.

# ***The Report***

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## **Section 1 Introduction**

### ***1.1 Mental health and caring in the UK***

Mental ill health is very common; at any one time, around one in six people of working age suffer from one or other form of mental illness, most often anxiety or depression (Department of Health (DoH), 1999a). Furthermore, one person in 250 will have a psychotic illness such as schizophrenia or bipolar affective disorder (manic depression) (DoH, 1999a). As far as older people are concerned, around 10–15 per cent of the population aged 65 and over will have depression, and approximately 600,000 people have dementia (DoH, 2001). This latter figure represents 5 per cent of the total population aged 65 and above, and increases to 20 per cent of the population aged 80 and over. Trends suggest a sharp growth in the ageing population, especially in the 'old elderly' category (those aged 75 and above). The proportion of that group who are also dependent is likewise growing (Phillips, 1994). It is estimated that by 2026 some 840,000 people in the UK will suffer from dementia, rising to 1.2 million by 2050 (DoH, 2001).

New estimates suggest there are around 6.8 million adult carers in 5 million households in Britain who care for and support disabled or sick relatives, or elderly people (Office of National Statistics (ONS), 2002). Up to 1.5 million people may be involved in caring for a relative or friend with a mental illness or some form of dementia (figures based on ONS, 2002). About half of those who have severe mental illness live with, and are supported by, family and friends (DoH, 1999a). Unless the amount of care provided by statutory services increases dramatically, there is likely to be greater pressure for support to be provided by (informal) carers in the future. However, participation in the labour market is expanding among middle-age women, the group that has traditionally been the main source of such care (DoH, 1999b). This trend has the potential to reduce the supply of carers, at the same time as demand is increasing.

### ***1.2 Policy context***

Recently, there have been a number of important policy initiatives aimed at carers. The Carers (Recognition and Services) Act (1995) and the Carers and Disabled Children Act (2000) respectively established, and then strengthened, carers' rights to an assessment of their own ability to provide care where they provide (or intend to provide) substantial care on a regular basis. Both pieces of legislation covered children and young people undertaking significant caring activities. The needs of young carers identified under the legislation can be

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met under local authorities' duties under Section 17 of the Children Act (1989), where they can be treated as 'children in need' and expect support and assistance via the Children Act in the event that resources are not forthcoming under other legislation (Becker *et al.*, 1998).

The national strategy for carers, *Caring about Carers* (DoH, 1999b), is further recognition of the key role carers play in supporting individuals in the community. The national strategy comprises three strategic elements: information, support and care. The Carers Special Grant was established to support the implementation of the strategy. Ring-fenced funding of £140 million was made available to local authorities to help them develop a wider range of services to give carers a break from their caring responsibilities. Many carers face problems in terms of their own physical and mental health. The national strategy (DoH, 1999b: 58) refers to an American study that showed that 80 per cent of carers of people with dementia were themselves suffering from chronic fatigue, depression or other psychological problems. Enabling carers to have time to themselves is seen as essential in reducing the psychological and emotional stress that many face.

The government has recently introduced the National Service Framework (NSF) for Mental Health (DoH, 1999a). The NSF covers the mental health needs of working-age adults up to 65, and specifically addresses unacceptable variations in services across England. The framework sets out seven 'standards' in five main areas which local health and social care communities have to agree to. Standard 6, 'Caring about Carers', focuses on carers – including young carers – of people who are mentally ill. The NSF emphasises that the needs of those caring for people with severe mental illness or dementia are especially high, and that there is evidence to suggest that carers are not receiving the services they need to support them in their caring role. The NSF states that all individuals who provide regular and substantial care for a person on Care Programme Approach (CPA) should:

- have an assessment of their caring, physical and mental health needs, repeated on at least an annual basis
- have their own written care plan that is given to them and implemented in discussion with them.

More recently, the government has published the NSF for Older People (DoH, 2001), which covers the needs of older people with mental health problems. This NSF also places a high priority on support for carers of older people with mental health problems, stating that carers' needs should be considered an integral part of the way in which services are provided for older people. Standard 7 is specifically concerned with services for older people with dementia and depression, as well as those older people who have severe mental illness due to a psychotic illness. The service model set out in Standard 7 states that a comprehensive mental service for older people will involve five different components, one of which is 'support for carers' (DoH, 2001: 103).

Some common themes relating to carers' needs in terms of physical and mental health and practical help emerge in the national strategy for carers (DoH, 1999b) and the two NSFs (DoH, 1999a; 2001). As well as stressing the need

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and requirement to undertake carer assessments, specific support services are emphasised:

- the provision of accessible and relevant information on available services, the specific disease and appropriate health care and treatments
- education and training programmes
- access to support groups
- short-term breaks
- interventions targeted at the whole family, such as family therapy and family counselling.

Local and national telephone help-lines, for example NHS Direct and the more specialist ones like SANEline, CALM and the Alzheimer's Helpline are promoted as valuable. Underlying principles and hallmarks of good services include characteristics such as comprehensive, multidisciplinary, well co-ordinated, accessible, responsive and individualised.

### ***1.3 Background to the scoping study***

The establishment of the National Institute for Clinical Excellence (NICE) and the introduction of clinical governance highlight the importance attached by government to the implementation of research-based evidence at both national and local levels (DoH, 1997: 57). A strong knowledge base is essential to help inform decision making by policy-makers, managers, practitioners, and users of health care. To help develop the knowledge base, there is a need to identify what further research and development work should be commissioned on services aimed specifically at carers for people with mental health problems. Evidence is also required to support the



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implementation of Standard 6 and Standard 7 in the NSFs for Mental Health and Older People respectively.<sup>1</sup> The NHS Service and Delivery Organisation (SDO) R & D Programme commissioned the Social Policy Research Unit at the University of York to undertake a scoping review on the effectiveness and cost-effectiveness of services to support carers for people with mental health problems. Our remit included services to support carers for adults of working age with serious mental health problems and carers for older people with mental health problems. Given that children and young people are known to care for people with mental health problems (Young Carers Research Group (YCRG), 2001), it was also necessary to collect evidence concerning services specifically targeted at this group.

The overall aim of the scoping exercise was to advise the SDO programme as to what further research and development work should be funded in this area. Our recommendations are based on evidence collected from a review of published and unpublished studies, and a consultation exercise involving national mental health, older people's and carers' organisations, as well as local bodies engaged in delivering the two NSFs.

The present report contains the findings of the literature review. The consultation exercise is reported in full in the accompanying *Consultation Report*. A third report, the *Overview Report*, draws together the key themes and issues relating to research into the effectiveness of interventions and services for carers of people with mental health problems that have emerged in the two complementary strands of work. This material is used to inform the recommendations made for future research and development work.

The present report reviews a wide range of studies evaluating interventions and services for carers of people with mental health problems, discusses issues relating to the effectiveness and cost-effectiveness of interventions, and provides insight into areas where there are gaps in knowledge. We make links from the evidence from the review, current policy in this area and recommendations for future research. The report is organised as follows. The next section, Section 2, describes the methodology for the review and the search strategy. Section 3 maps the extent, nature and distribution of the studies included in the review and leads into the more detailed analysis in Section 4. The economic aspects of the interventions to support carers are discussed in Section 5. This leads, in Section 6, to a short discussion of conceptual and commissioning issues relating to notions of effectiveness and cost-effectiveness. Section 7 discusses the findings, the gaps in research and areas where there is a need for more research.

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<sup>1</sup> The NHS Centre for Reviews and Dissemination at the University of York recently published a report documenting a scoping review of the evidence on the effectiveness of mental health care services (Jepson *et al.*, 2001). They found just four systematic reviews relevant to Standard 6 of the NSF for Mental Health. One of these focused on family interventions, two on respite care and the fourth looked at a diversity of interventions. The authors found no systematic reviews had been undertaken in relation to the provision and implementation of care plans.

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### **Note on terminology**

Similar terminology has been used throughout all three reports documenting the study. The term 'carer' has been used rather than 'informal carer' or 'care-giver'. Likewise, the terms 'care recipient', 'person supported', 'person with a mental health problem', 'service user' or 'patient' have been used to refer to the person being cared for.

## **Section 2 Methods**

### **2.1 Introduction**

This section sets out how we scoped the literature in the area under examination. The methods used were designed to identify empirical studies that addressed the central research question: 'What is known from the existing literature about the effectiveness and cost-effectiveness of services to support carers of people with mental health problems?'

There is no definitive way to undertake a scoping study, and the methods used drew on established literature review procedures. However, a major component of a scoping study is to 'map' or identify the literature that currently exists in the field of interest (Mays *et al.*, 2001), rather than address the issue of quality of individual studies. Thus the review did not seek the 'best evidence' (Slavin, 1995), but instead sought to map the whole literature and report on those studies most relevant to the above research question as a means to identify gaps.

The following discussion describes the first three stages of the review:

- identifying relevant studies
- developing inclusion and exclusion criteria
- the process of data extraction.

### **2.2 Identifying relevant studies**

The literature review aimed to be comprehensive in identifying all studies relevant to the effectiveness of services to support carers of people with mental health problems. Consequently we aimed to locate a wide variety of research dealing with the issue of effectiveness in terms of study design, mental health focus, intervention site, and intervention type. To achieve this, a fivefold search strategy was adopted as follows.

- Develop search strategy for electronic databases.
- Identify key journals for hand searching.
- Undertake Internet searches of key sites.
- Identify key organisations for unpublished material.
- Drawing on expertise through the consultation exercise.

The identification of relevant literature was limited by two criteria from the outset. Only studies published between January 1985 and October 2001 were included. Studies not written in English were excluded.

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All citations were downloaded or entered by hand into an Endnote<sup>2</sup> database and scanned for relevance according to pre-defined inclusion and exclusion criteria (see below).

### **2.2.1 Search strategy for electronic databases**

Electronic databases generated the majority of studies included in the literature review (see Table 2.1 below). The search strategy was devised in order to maximise the number of relevant studies included in the scoping exercise while seeking to minimise the number of irrelevant studies.

It should be recognised that searching this topic area can be problematic due to the range of terms describing mental health problems, the limitations of electronic abstracting services, and a lack of agreed terms for carers, which can be complicated by different kinship relations as well as international differences – for example, ‘carer’ in the UK and ‘caregiver’ in North America (Charlesworth, 2001).

The search strategy developed reflected four main areas of interest:

- studies relating to carers
- studies of interventions for carers
- mental health problems
- issues of effectiveness and/or cost-effectiveness

drawing on lists of possible synonyms for these areas of interest. An information officer in the NHS Centre for Research and Dissemination (CRD) at the University of York conducted searches on the following databases.

#### ***CD-ROMS***

- AMED (1985–2001/07)
- ASSI (1980–2001)
- BNI (1994–2001/07)
- Cinahl (1982–2001/10)
- Cochrane Library: Cochrane Controlled Trials Register (Issue 4 2001)
- Cochrane Library: Cochrane Database of Systematic Reviews (Issue 4 2001)
- EMBASE (1984–2001/10)
- HMIC – King’s Fund Database, HELMIS, Dhdata (1979 – current)
- Medline (1981–2001/10)

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<sup>2</sup> Endnote is a reference database that stores, manages and searches for bibliographic references.

## ***Services to Support Carers of People with Mental Health Problems***

- SIGLE (2001)
- Social Science Citation Index (SSCI) (1985–2001)
- Sociological Abstracts 1986–2001/09

### ***Internet resources***

- Caredata  
<http://www.elsc.org.uk/uc.htm>
- Database of Abstracts of Reviews of Effectiveness (DARE)  
<http://www.york.ac.uk/inst/crd>
- Health Technology Assessment Database (HTA)  
<http://www.york.ac.uk/inst/crd>
- NHS Economic Evaluations Database (NHS EED)  
<http://www.york.ac.uk/inst/crd>

The search strategy used terms to denote ‘carer’ (caregiver, caretaker, carer) combined with a range of mental health terms and service interventions to generate references. A filter was subsequently applied to these to identify those references specifically addressing cost-effectiveness (see Appendix 2 for the full details of the terms used).

In order to seek as comprehensive a list of studies as possible, four other strategies for identifying literature were also undertaken. These are described below.

### **2.2.2 Hand searching**

Because electronic databases may be incomplete or inaccurate, hand searching of the following journals was undertaken:

- *British Journal of Psychiatry*
- *Journal of Mental Health*
- *Journal of Dementia Care*
- *Journal of Advanced Nursing*.

The most common journal titles found in the database search were: *Gerontologist*, *Journal of Gerontological Social Work*, *Ageing and Mental Health* and *American Journal of Alzheimer’s Disease*. Not all of these were available for hand searching at the University or its sister libraries. We recommend that any future work in this area includes a hand search of these journals as a matter of priority.

### **2.2.3 Internet searches**

The Internet is a source of up-to-date and unpublished material, although current search engines tend to provide many irrelevant sites.

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Given the limited time for this study, only a small number of key websites associated with carers' organisations and government departments were searched:

- National Schizophrenia Fellowship: [www.nsf.org.uk](http://www.nsf.org.uk)
- Carers UK: [www.carersuk.demon.co.uk](http://www.carersuk.demon.co.uk)
- Government website for carers: [www.carers.gov.uk](http://www.carers.gov.uk)
- Alzheimers Society: [www.alzheimers.org.uk](http://www.alzheimers.org.uk)
- Princess Royal Trust for Carers: [www.carers.org](http://www.carers.org)
- Carersnet: [www.carersnet.org.uk](http://www.carersnet.org.uk)
- Carers UK Northern Ireland: [www.carersnorthern.demon.co.uk](http://www.carersnorthern.demon.co.uk)
- Department of Health: [www.doh.gov.uk](http://www.doh.gov.uk)
- King's Fund: [www.kingsfund.org.uk](http://www.kingsfund.org.uk)
- World Fellowship for Schizophrenia: [www.world-schizophrenia.org](http://www.world-schizophrenia.org)

### **2.2.4 Consultation with key organisations and informants**

The following organisations working in the field were contacted with a view to hand searching libraries or identifying unpublished work:

- Sainsbury Centre for Mental Health ([www.scmh.org.uk](http://www.scmh.org.uk))
- National Schizophrenia Fellowship ([www.nsf.org.uk](http://www.nsf.org.uk))
- Carers UK ([www.carersuk.demon.uk](http://www.carersuk.demon.uk))
- MIND ([www.mind.org.uk](http://www.mind.org.uk))
- Mental Health Foundation ([www.mentalhealth.org.uk](http://www.mentalhealth.org.uk))
- King's Fund ([www.kingsfund.org](http://www.kingsfund.org)).

In the course of discussions with key informants and as part of the questionnaire survey (see *Consultation Report*) there were also opportunities for individuals to identify unpublished research, or research they had found particularly useful in their work. Only four such additional studies were identified.

### **2.2.5 Reference checking**

References identified in all studies were checked to ensure they had been included in the scoping exercise. This process did generate new references, although a saturation point was reached where no new references were being identified. All the additional references were added to the Endnote database and included in the review. A number of studies were identified at too late a stage to be included and are listed in Appendix 3. It should be noted that the full report or article has not been seen in these cases and therefore overall relevance is difficult to determine.

The search strategy identified 3867 references in total. A number of these (112) were identified as the study progressed and these were treated in the same way as those generated in the initial search. However, it was clear that the search terms had generated a number of studies that were not relevant to

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the main research questions. This underpinned the view that this topic area can be difficult to search, given the range of mental health problems and definitions of caring that might be included. There is also a difficulty in identifying through search terms the person or group for whom a particular service is provided as there may be some overlap between a service that is provided primarily for the care recipient with possible benefits for carers. It was felt to be important to include these overlapping services in any attempt to consider issues of effectiveness and cost-effectiveness and consequently it was recognised that a large number of studies could be identified that would require further investigation to determine whether they were relevant to the scoping study. To that end, discrete inclusion and exclusion criteria were applied to all the studies as they were identified.

### ***2.3 Inclusion and exclusion criteria***

Inclusion and exclusion criteria were developed and applied to those studies written in the English language and published between January 1985 and December 2001 that represented a 'best fit' with the central research question: 'What is known from the existing literature about the effectiveness and cost-effectiveness of services to support carers of people with mental health problems?'

Inclusion criteria:

- *study type*: empirical work that evaluated the effectiveness or cost-effectiveness of services to support carers of people with mental health problems
- *intervention type*: any intervention directed towards carers of people with mental health problems, including dementia
- *care recipient group*: any care recipient group comprising individuals 18 years of age and over with any mental health problem
- *carer group*: carers of any age; carers of people with mental health problems.
- Exclusion criteria:
  - *study type*: non-empirical work
  - *intervention type*: interventions directed towards care recipients only that report no implications for carers
  - *non-English-language references*
  - *nature of reference*: book reviews, commentaries and PhD theses.

The inclusion and exclusion criteria were applied to all 3867 references using abstracts or the full report or article where available. All research reports, regardless of the type of intervention or research methods used, were included in the scoping study in order to provide as full a picture as possible of the range and type of services for carers of people with mental health problems, as well as the type of research undertaken in this field.

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Three types of studies were identified and classified according to their degree of 'fit' with the research question.

- *Type A* studies: empirical studies of effectiveness or cost-effectiveness of services for carers of people with mental health problems. These represented the best fit with the research question and formed the basis for the literature review.
- *Type B* studies: empirical studies of effectiveness or cost-effectiveness of services for carers. These were reviewed with a view to identifying particular features of 'effectiveness' or 'cost-effectiveness' that might have been missing in studies of carers of people with mental health problems. However, these studies were not helpful, since they did not reveal any new kinds of data. Consequently, they were not used in the final review.
- *Type C* studies: empirical studies of services that have implications for carers of people with mental health problems. Subsequent analysis of these studies revealed that fragments of a number of different literatures had been picked up by the search strategy, but that none of these were comprehensive enough to be included in the scoping review. The Type C studies covered issues around utilisation of services, development of organisations and interventions, the needs of carers, interventions directed towards care recipients, and policy review documents. Some of these Type C studies were useful as background material for the literature review (see Table 2.2), but the majority were not analysed.

In sum, only the Type A studies were included in the literature review, where these represented the best fit with the research question. Neither the Type B nor the Type C studies were included, first because they did not provide any significantly new material in relation to understanding the effectiveness or cost-effectiveness of services for carers, and secondly because many of the studies represented 'fragments' of larger literatures that required some analysis in their own right.

The process of applying inclusion and exclusion criteria allowed us to consider the range of possible literatures that existed in relation to carers of people with mental health problems. However, the studies finally identified for inclusion in the review were those focusing on the effectiveness and cost-effectiveness of services and interventions.

### ***2.4 Results of the literature search***

The search strategies yielded a total of 3867 citations. Of these, 804 were considered to meet the inclusion criteria. Full reports were obtained for 684 (85 per cent) of these. Once full reports had been obtained, a further 311 were found not to meet the inclusion criteria. Some 109 studies were not retrieved because they were not available through library sources, or were identified too late to be included in the review (see Appendix 3). In total, 204 studies were classified as Type A studies and are reported in subsequent sections. Of these 204 references, only 13 contained economic data. An additional 9 references have been included in the overall discussion of cost-effectiveness where these



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were pertinent to the relevant methodological issues. The analysis of these studies was undertaken by the health economist and the findings are reported in Section 5.

Table 2.1 shows the proportion of studies found by the different bibliographic sources used in the search strategy. The majority of references were found on the electronic and specialist bibliographic databases. The most productive of these were Medline and Embase, through which over half the references were found (see Appendix 1). Least productive were attempts to locate unpublished reports through organisations, Internet searches and personal contacts.

**Table 2.1 Number of studies of services for carers of people with mental health problems found within different bibliographic sources (N = 3867)**

<b>Bibliographic source</b>	<b>N</b>	<b>%</b>
Electronic and specialist bibliographic databases and registers	3 755	97
Hand searches	15	0.4
Reference checking	93	2.4
Internet searches	0	0
Personal contacts	4	0.2

The literature that was identified in the scoping study was of different types. The review itself was based on the Type A studies (see above). Useful background material was gathered from a range of other material as shown in Table 2.2.

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**Table 2.2 The distribution of studies of evaluations of services for carers of people with mental health problems according to study type (N = 373)**

<b>Study type</b>	<b>N</b>	<b>%</b>
Intervention studies (Type A)	204	54.8
Policy reviews and other background papers (from Type C studies)	65	17.4
Literature review	45	12.1
Evaluation methods	30	8.0
Additional studies of cost-effectiveness	29	7.7

### ***2.5 Data extraction/ classifying relevant studies***

The analysis involved extracting relevant data from all 204 studies in the review. These comprised information on:

- the intervention type, and comparator (if any)
- the study sample
- the care recipient group
- aim(s) of study
- research methods
- the duration of intervention
- outcomes
- the country where the study was set.

Further data extracted only for the economic analysis included:

- types of costs included
- whether cost data were collected retrospectively or prospectively
- currency used to report findings
- measures of benefits reported
- whether there was a synthesis of costs and benefits.

These data formed the basis of the analysis.

## **Section 3 Scoping the field: initial mapping**

This section maps the extent, nature and distribution of the studies included in the review in terms of:

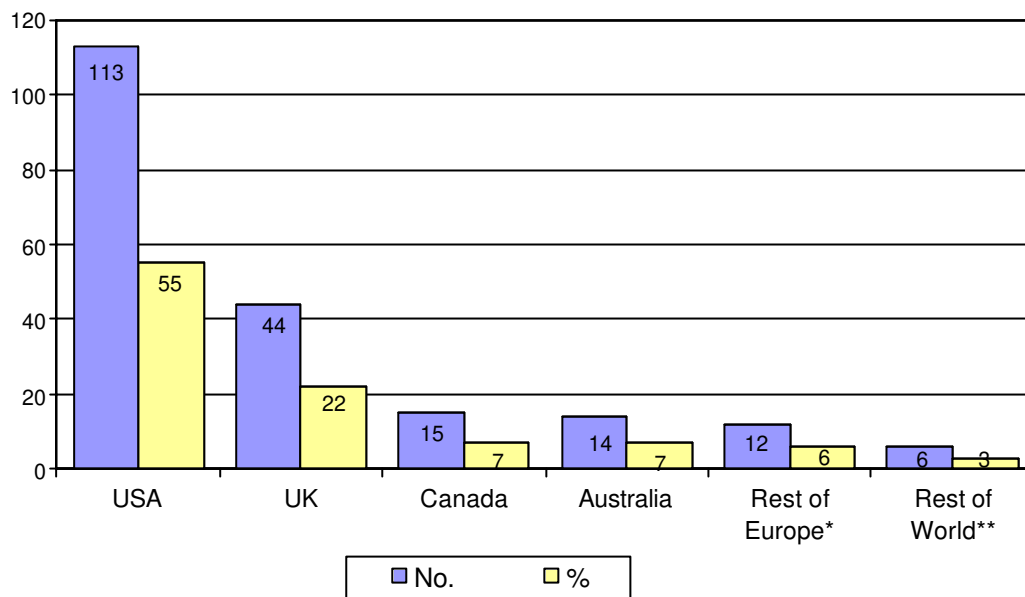
- geographical distribution
- condition group
- geographical distribution of condition group
- the range of interventions included in the review
- interventions implemented specifically in the UK
- research methods adopted and measures of effectiveness.

### ***3.1 Geographical distribution of studies of evaluations of interventions for carers of people with mental health problems***

Figure 3.1 shows the number and proportion of research reports that evaluated interventions for carers of people with mental problems, including dementia, according to the country in which the intervention was implemented. The majority of papers described interventions carried out in the USA (55 per cent). In comparison, a far smaller proportion of reports derived from the UK (22 per cent). Canada and Australia each accounted for 7 per cent of the studies. Studies from the rest of Europe and the rest of the world accounted for the remainder.

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**Figure 3.1** Distribution of studies of evaluations of interventions for carers of people with mental health problems, by country (N = 204)



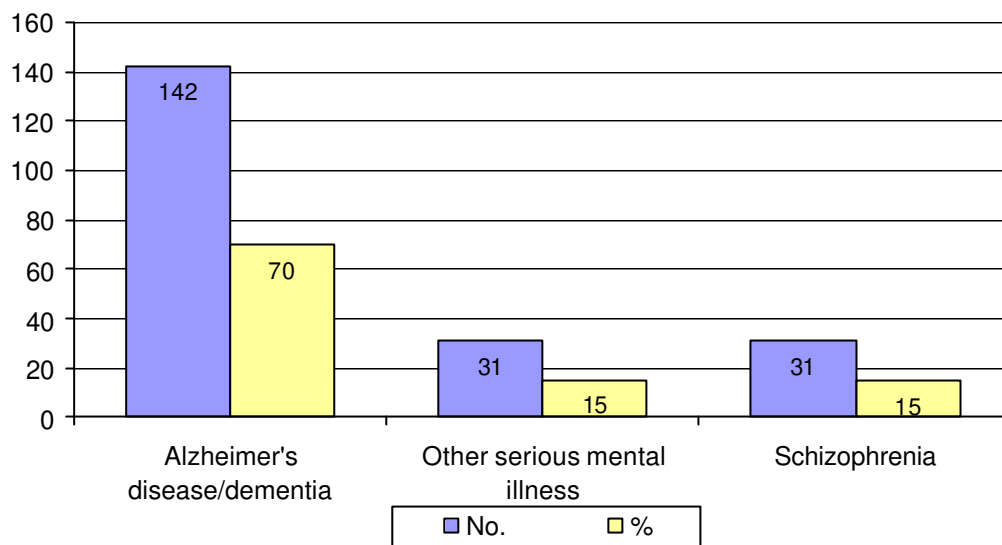
\* Netherlands (4); Italy (3); Belgium (1); Sweden (1); Ireland (1); Germany (1); Spain (1)

\*\* Japan (2); China (2); Malaysia (1); Hong Kong (1)

### 3.2 Care recipient group

Figure 3.2 shows the number and proportion of studies according to the diagnosis or condition of the person supported according to three categories: Alzheimer's disease and related dementias; schizophrenia; other serious mental illness (as well as unspecified conditions – this group includes mental illnesses such as depression and bipolar disorder). The majority of interventions (70 per cent) were designed for carers of people with Alzheimer's disease or other types of dementia.

**Figure 3.2 Number and proportion of studies according to care recipient group (N = 204)**



### **3.3 Geographical distribution of studies of evaluations according to care recipient group**

Table 3.1 shows the number and proportion of studies by country for each of the three care recipient groups. The majority of studies focused on carers of people with Alzheimer's disease or other dementia have been conducted in the USA (44 per cent). The UK has been the setting for most of the studies relating to schizophrenia (6.5 per cent). In the USA, there has been a clear emphasis on dementia rather than schizophrenia or other types of mental illness. In comparison, research in the UK has been more evenly spread: Alzheimer's disease (41 per cent); schizophrenia (32 per cent); other serious mental illness (27 per cent). Of the 12 UK studies in the category 'Other serious mental illness', no studies were identified that focused on acute or chronic depression, eating disorders, anxiety or substance abuse. However, some people with depression or anxiety were included among the participants in a small number of studies.

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**Table 3.1 Geographical distribution of studies according to care recipient group (N = 204)**

	Alzheimer's disease/ dementia		Schizophrenia		Other serious mental illness	
	No	%	No	%	No	%
USA	90	44	8	4	15	7
UK	18	9	14	6.5	12	6
Canada	13	6	1	0.5	1	0.5
Australia	9	4	4	2	1	0.5
Rest of Europe	* 10	5	–	–	** 2	1
Rest of world	† 2	1	†† 4	2	–	–
Total	142	70	31	15	31	15

\* Italy (3); Netherlands (2); Ireland (1); Germany (1); Spain (1); Sweden (1); Belgium (1)

\*\* Netherlands (2)

† Hong Kong (1); Japan (1)

†† China (2); Malaysia (1); Japan (1)

### ***3.4 Categorising the interventions and services***

Many different types of interventions and services have been developed to help support carers, and the research studies included in this review reflect this heterogeneity. Altogether, the review is based on 204 research reports, just 13 of which have an economic element. Services ranged from day care or home-based or institution-based respite, which offered carers the opportunity to take a (short) break from caring, to interventions such as counselling or education. Some interventions were aimed at the individual carer (for instance, one-to-one counselling), while others were delivered in a group format (such as support groups). Some were of interventions with both the carer and person supported together (for example, educational or training programmes), while others were targeted at all family members (for instance, family therapy). Some interventions recognised the fact that two people are involved in caring, and aimed to have a beneficial impact on both the carer and the person supported (for example, a gentle hand treatment for dementia patients). Other interventions attempted to use the carer as an 'agent of change' (Charlesworth, 2001) and carers were trained in using particular care-giving skills with the person supported (for instance, cognitive stimulation).

To create some order in complex and unwieldy material, interventions were grouped together. Categorisation was difficult: there was great diversity and/or overlaps; descriptions of some interventions were insufficient; authors' definitions did not always appear justifiable and/or consistent.

Table 3.2 shows the classification scheme adopted, as well as the number of studies according to each intervention category. The most common intervention studied related to education of different kinds (36 per cent), followed by breaks from caring (18 per cent). In comparison with family

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interventions (10 per cent) and mutual support and social activity groups (9 per cent), counselling was less frequent (4 per cent).

**Table 3.2 Studies of evaluations of interventions for carers of people with mental health problems (N = 204)**

	All studies		Studies with an economic aspect	
	N (204)	%	N (13)	%
<b>Educational interventions</b>	73	36	1	8
• education	29	15	–	–
• training	21	10	1	8
• psychoeducational interventions	23	11	–	–
<b>Breaks from caring</b>	36	18	2	15
• day care services	12	6	1	8
• in-home respite care	4	2	–	–
• institutional respite	5	3	–	–
• mixed respite care services	15	7	1	8
<b>Family interventions</b>	20	10	3	23
<b>Mutual support and social activity groups</b>	18	9	–	–
<b>Telephone and computer-based services</b>	16	8	1	8
<b>Multidimensional approaches to caring interventions</b>	15	7	4	31
<b>Counselling</b>	9	4	–	–
<b>Miscellaneous*</b>	8	4	2	15
<b>Domiciliary care services</b>	4	2	–	–
<b>Physical environment</b>	3	1	–	–
<b>Supporting carers through memory clinics</b>	2	1	–	–

\* Described in detail in Section 4.11

The typology derives from one used in a recent systematic review of interventions for carers of people with dementia (Cooke *et al.*, 2001). The 11 classification categories adopted reflect the types of interventions prioritised for mental health carers in government policy. For instance, the national strategy for carers (DoH, 1999b) and NSF for Older People (DoH, 2001) all emphasise breaks for carers, educational and training programmes, family interventions and support groups. The groupings are also helpful in terms of identifying gaps in the literature and areas for further research. There is no 'psychosocial' category, reflecting the point that authors tend to use this as a broad heading to cover a very wide range of types of interventions, and what can be described by one researcher as a psychosocial intervention is not necessarily defined by another in the same way.

### **3.5 Evaluation studies of interventions set in the UK**

Table 3.3 shows the number and proportion of evaluation studies of interventions for carers set in the UK. The majority of papers described interventions aimed at the family as a whole (30 per cent). Educational interventions of different types and breaks from caring accounted for 25 per cent and 18 per cent respectively.

**Table 3.3 UK studies evaluating interventions for carers of people with mental health problems (N = 44)**

	<b>N (44)</b>	<b>%</b>
<b>Family interventions</b>	<b>13</b>	<b>30</b>
<b>Educational interventions</b>	<b>11</b>	<b>25</b>
• education	8	18
• training	2	5
• psychoeducational interventions	1	2
<b>Breaks from caring</b>	<b>8</b>	<b>18</b>
• day care services	1	2
• in-home respite care	1	2
• institutional respite	1	2
• mixed respite care services	5	12
<b>Multidimensional approaches to caring interventions</b>	<b>4</b>	<b>9</b>
<b>Domiciliary care services</b>	<b>3</b>	<b>7</b>
<b>Miscellaneous*</b>	<b>2</b>	<b>5</b>
<b>Mutual support and social activity groups</b>	<b>1</b>	<b>2</b>
<b>Counselling</b>	<b>1</b>	<b>2</b>
<b>Supporting carers through memory clinics</b>	<b>1</b>	<b>2</b>
<b>Telephone and computer-based services</b>	<b>–</b>	<b>–</b>
<b>Physical environment</b>	<b>–</b>	<b>–</b>

\* Carer-held documentation pack; assertive outreach programme

### **3.6 Type of research methods used to evaluate interventions for carers of people with mental health problems**

As Table 3.4 shows, the majority of studies (80 per cent) used quantitative methods. Of these, randomised controlled trials (RCTs) comprised 33 per cent of studies; non-randomised controlled trials accounted for 20 per cent; before-and-after studies (uncontrolled), 31 per cent; retrospective/post-intervention measures, 16 per cent. The remaining 20 per cent of studies used mainly mixed methods, or qualitative methods. Researchers using mixed methods collected both quantitative and qualitative data using, say, standard outcome measures or a postal survey together with in-depth interviews, focus group work or



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documentary analysis. Qualitative studies tended to involve in-depth interviews with relatively small numbers of participants.

Less than 20 per cent of the studies included in the review were comparative studies that compared the efficacy of one type of intervention against another (a very small number of these were RCTs). The vast majority of studies were experimental or quasi-experimental. Those that took place in 'natural' settings tended to be of existing support groups for carers or established clinical services. Just over one-quarter of studies included follow-up at three months or over. Longer-term follow-up of two years and over was rare (5 per cent).

**Table 3.4 Number and proportion of studies according to type of research (N = 204)**

	N	%
<b>Quantitative methods</b>	<b>162</b>	<b>80</b>
• RCTs	53	33
• before-and-after studies (uncontrolled)	51	31
• non-randomised controlled trials	33	20
• post-intervention measures	25	16
<b>Mixed or multiple methods</b>	<b>22</b>	<b>11</b>
<b>Qualitative methods</b>	<b>13</b>	<b>6</b>
<b>Other*</b>	<b>7</b>	<b>3</b>

\* e.g. content analysis, secondary data analysis, inadequate description of methods

### ***3.7 Measures of effectiveness and cost-effectiveness***

Seventy per cent of the studies included in the review used standard outcome measures as a way to evaluate the effectiveness of interventions for carers of people with mental health problems. Outcomes most commonly measured were carer burden, stress, coping, physical health, emotional well-being, depression, quality of life and knowledge levels. The outcome measures used were mainly 'off-the-shelf' instruments, in particular the General Health Questionnaire, the Burden Interview, the Center for Epidemiological Studies Depression Scale and the Positive and Negative Affect Schedule. If researchers felt existing measures were not fully appropriate for their particular focus of interest, they took subsets of different measures and combined them into a new pool of items. Alternatively, researchers developed their own scales, tailor-made for the purpose.

Alternative, and/or additional, ways to assess the effectiveness of interventions included programme evaluations, satisfaction surveys, service utilisation rates, relapse rates, admissions to institutional care or hospital, practitioners' observations of outcomes. Most of the studies with an economic component included health care costs and social services costs. One study valued carer time; two assessed changes in carer earnings.

### ***3.8 Summary of characteristics of available research***

Some 204 evaluation studies of interventions for carers of people with mental health problems were included in the review. The mapping exercise shows that:

- the majority of studies were set in the USA, and focused on people with Alzheimer's disease or other form of dementia
- educational interventions were most commonly studied, followed by breaks from caring and then family interventions
- UK studies focused on interventions for carers of people with schizophrenia; family intervention studies predominated
- studies were mainly of single interventions rather than multidimensional approaches
- most studies were experimental or quasi-experimental, using a repeated measures design; studies using mixed or qualitative methods were in the minority
- few studies collected follow-up data to address longer-term effects
- most studies used standard outcome measures to assess the effectiveness of interventions; outcomes relating to care burden, stress and physical and emotional health were commonly measured.

Having mapped out the research reports included in the scoping study and explained the categorisation groups, we can now present in the next chapter our review of the studies.

## **Section 4 Review of interventions and services for carers**

This section analyses the 204 research reports included in the scoping study, categorised into the 11 intervention groups shown in Table 3.2. The 11 categories are ordered as follows:

- Breaks from caring (Section 4.1)
- Educational interventions (Section 4.2)
- Family interventions (Section 4.3)
- Mutual support and social activity groups (Section 4.4)
- Counselling (Section 4.5)
- Telephone and computer-based services (Section 4.6)
- Domiciliary care services (Section 4.7)
- Physical environment (Section 4.8)
- Supporting carers through memory clinics (Section 4.9)
- Multidimensional approaches to caring (Section 4.10)
- Miscellaneous (Section 4.11).

In the light of the large number of studies, we devised a template to help report the findings for each category. The layout of the template is as follows. First, there is a small table detailing:

- the identification number of each study (to be cross-referenced with summary Tables 1–15 in Appendix 4)
- the care recipient group, under three headings:
  - Alzheimer’s disease/dementia
  - schizophrenia
  - other serious mental illness (which includes illnesses such as bipolar disorder, depression, anxiety)
- the countries in which the studies were set
- main measures of effectiveness (standard outcome measures; programme evaluations/satisfaction surveys).

The material that follows documents descriptive characteristics of studies included in the review, together with more substantive issues including effectiveness and cost-effectiveness.

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The nine headings used are:

- Interventions
- Sample sizes
- Participants
- Research methods
- Outcomes
- Evidence relating to effectiveness
- Economic aspects
- UK studies
- Gaps in the research.

It is important to note that under the headings 'Evidence relating to effectiveness' and 'Economic aspects', we report the opinion of the authors of the research rather than our own views on the impact of the intervention in question. Each different intervention group has been reported so that it can stand on its own, for readers who have a special interest in particular types of interventions.

Summary tables documenting fuller information about all the studies included in each of the different intervention groups can be found in Tables 1–15 in Appendix 4. These tables include the following details:

- study identification number (these numbers are referenced in the main text of this report as, for example, <sup>123</sup>)
- author(s)
- study sample
- care recipient group
- research methods
- intervention type
- duration of intervention
- outcomes
- setting.

## **4.1 Breaks from caring (N = 36)**

### **Day care services (N = 12)**

<b>Study identification code numbers</b>	34, 35, 37, 78, 118, 121, 156, 181, 199, 200, 230, 248
<i>(see Table 1 in Appendix 4)</i>	
<b>Care recipient group</b>	AD and dementia (11), schizophrenia (0), other serious mental illness (1)
<b>Setting</b>	USA (7), Australia (2), UK (1), Belgium (1), Hong Kong (1)
<b>Main measures of effectiveness</b>	Standard outcome measures (7), programme evaluation/satisfaction surveys (5)

**Interventions:** Studies examined adult day programmes in a number of different countries. Some studies undertaken in the USA focused on centres that adopted a social model and provided daytime social activities and supervision, and/or programmes that adopted a medical model and delivered skilled nursing services to clients. One study<sup>199</sup> was of a national, four-year programme that operated a total of 24 day centres for people with dementing illnesses, serving both urban and semi-rural sites in 13 states. One of the Australian studies<sup>35</sup> looked at day care programmes specifically for people with dementia; such programmes offered the patients activities suited to their cognitive limitations.

**Sample sizes:** Sample sizes ranged from just one<sup>181</sup> to 324<sup>78</sup>. They tended to fall into one of two extremes: either relatively small (below 50) or relatively large (above 200).

**Participants:** A number of the interventions were aimed at primary carers; very often, there were more female participants than male. Ages varied: for example in one study<sup>121</sup>, the age range of carers spanned 27–88 years. One study<sup>230</sup> involved patient–carer dyads. The majority of studies were focused on respite care for people with dementia.

**Research methods:** Most studies used quantitative methods, although few used a control group. pointing out that in practice this can be difficult and/or unethical to do in studies that evaluate services. Some studies employed a repeated measures design, including follow-up in both the short term and in the longer term. There were problems with attrition. For instance, of the 261 people who completed the initial interview in one study<sup>230</sup>, 175 (65 per cent) completed the three-month follow-up interview and just 90 (34 per cent) completed the interview at the 12-month follow-up stage. One study<sup>230</sup> compared adult day care services based on a medical model with services based on a social model. Three studies<sup>35, 78, 121</sup> involved comparisons between carers who used adult day care services with carers who were non-users.

**Outcomes:** Studies evaluated different aspects of the use of adult day care for carers, in particular the impact on carers' stress and well-being, the perceived benefits and drawbacks of day care, and barriers to use. Some

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studies also looked at the effect of day care attendance on the social and adaptive behaviours of the person cared for.

**Evidence relating to effectiveness:** A number of issues are raised in the studies of effectiveness of adult day care services. First there is a view expressed that both carer and patient can benefit from day care<sup>118, 181</sup> and that it is the benefits to the patient that encourage carers to use these services<sup>121</sup>. The latter finding has implications for the take-up of day care which may depend on persuading carers of the benefits of respite for the person they support. Second, some of the studies suggest that the high levels of reported carer satisfaction with day care services<sup>37, 156</sup> are not reflected in the results of pre- and post-test outcome measures where little or no improvement has been found<sup>35, 156</sup>. These studies contradict those that have found some evidence of long-term effects on carers, including one<sup>200</sup> that reported reduced levels of burden and another<sup>78</sup> reporting reduced levels of overload and depression at one-year follow-up. It might be surmised, therefore, that different models of day care service have potentially different kinds of benefits for carers. However, this hypothesis is not supported by a study<sup>34</sup> of different adult day care models that reported no significant differences in carer stress or well-being, or patient impairment across models.

Overall, the evidence regarding effectiveness of adult day care services is mixed, ranging from no evidence of effectiveness to claims for long-term benefits, although high levels of reported satisfaction with these services suggest that some carers may be benefiting from respite in ways that are not captured in existing research evidence.

**Economic aspects:** Only one study addressed the economic implications for this intervention<sup>200</sup>. Set in the UK, 179 patients with acute psychiatric illness were randomly assigned to either day hospital care or to routine inpatient care. 103 carers were assessed on two scales: carer burden was assessed using the Social Behaviour Assessment Schedule score and carer health was measured on the General Health Questionnaire (GHQ). Although no significant difference was found on the GHQ scale, carer burden was found to be significantly lower in the day patient group at the 12-month assessment. Since day care was found to cost less than inpatient care, the authors concluded that the intervention was cost-saving.

**UK studies:** The only UK study<sup>200</sup> looked at the cost-effectiveness of day and inpatient psychiatric treatments. Details are reported in the 'Economic aspects' section above.

**Gaps in the research:** There is a need for more comparative work on adult day care services to identify which carers, which patients and which models of service are most effective. Given the limited evidence for effectiveness deriving from the use of standard measures, consideration should be given to the use of qualitative methods and alternative outcome measures in this area.

Furthermore, only one study was identified that considered the benefits of adult day care for people with mental health problems other than dementia-related illnesses. The opportunities to expand the service to carers of people with other severe mental health problems need to be examined.

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### **In-home respite care (N = 4)**

<b>Study identification code numbers</b>	77, 117, 186, 214
<i>(see Table 2 in Appendix 4)</i>	
<b>Care recipient group</b>	AD/dementia/elderly (4), schizophrenia (0), other serious mental illness (0).
<b>Setting</b>	UK (1), USA (1), Canada (1), Sweden (1)
<b>Main measures of effectiveness</b>	Standard outcome measures (2), programme evaluation/satisfaction surveys (4)

**Interventions:** The interventions varied. The UK study<sup>117</sup> examined a scheme provided by Age Concern in which care attendants undertook in-home respite care with people looking after elderly, physically handicapped and sick people. In contrast, the Canadian study<sup>186</sup> evaluated a visiting/walking programme where an integral component of each visit was physical and/or psychological stimulation in the form of a walk or an outing. The Swedish research<sup>77</sup> examined an intervention where trained deacons in turn trained family carers of people with dementia and other volunteers. After their training, the volunteers substituted for the carers in their homes on a weekly basis.

**Sample sizes:** Sample sizes ranged from 24<sup>186</sup> to 80<sup>214</sup>.

**Participants:** One study<sup>77</sup> was aimed specifically at the principal carer; the age range of carer participants, mainly female, was 39–86 years. The study sample in the UK study<sup>117</sup> also consisted of more women than men. Care recipients in all four studies suffered from dementia. In the Swedish study<sup>77</sup>, data were also collected from other key stakeholders, namely deacons and volunteers.

**Research methods:** All the studies collected data (through measures and/or interviews) from participants both before and after implementation of the service.

**Outcomes:** The studies evaluated carer stress, coping, strain and burden. Researchers also looked at participants' satisfaction with programmes.

**Evidence relating to effectiveness:** The small number of studies and small sample sizes of these is indicative of the relative paucity of evidence regarding the effectiveness of in-home respite services. High degrees of satisfaction with services were reported in three studies<sup>77</sup>.

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<sup>117, 186</sup> and some improvement in perceived carer burden<sup>186</sup> and coping<sup>117</sup> were also reported.

The evidence from these studies does not support claims for the effectiveness of in-home respite, but neither can they be used to suggest that such services are not effective.

**Economic aspects:** No economic study addressing in-home respite was identified.

**UK studies:** As noted above, the one UK study<sup>117</sup> examined an in-home respite care scheme provided by Age Concern. Some 78 carers took part in the study, which took place over a 12-month period. Of these, 63 carers used the service; the 15 who did not provided a comparison group. Agents who referred clients to the service, primarily district nurses, social workers and GPs, also took part in the research.

**Gaps in the research:** The field of in-home respite remains under-researched. Experimental projects, such as the Circle Model<sup>77</sup> require further investigation and development. There is a paucity of evidence regarding the use of in-home respite by carers of people with mental health problems other than dementia.

### **Institutional respite (N = 5)**

<b>Study identification code numbers</b>	4, 6, 50, 182, 189
<i>(see Table 3 in Appendix 4)</i>	
<b>Care recipient group</b>	AD/dementia (3), schizophrenia (0), other serious mental illness (2)
<b>Setting</b>	USA (3), UK (1), Canada (1)
<b>Main measures of effectiveness</b>	Standard outcome measures (3), programme evaluation/satisfaction surveys (3)

**Interventions:** Five studies of institutional respite were included in the literature review. The respite services were offered in different settings including hospitals, medical centres and nursing homes. Inpatient stays from two days up to two weeks were available. The UK service<sup>182</sup> was different in that it was a night nursing service for elderly people suffering from dementia. One US intervention studied<sup>4</sup> was of a week-long annual respite 'camp' for all family members, including carers and the person supported.

**Sample sizes:** The sample sizes in all the studies were relatively small, ranging from 14<sup>189</sup> to 70<sup>4</sup>.

**Participants:** The studies collected data from carers' family members and/or care recipients. Carer participants were more often female than male, again with a varied age range. Two studies<sup>4, 189</sup> focused on people with mental illnesses; in one case patients were male veterans<sup>189</sup>. The respite camp study<sup>4</sup> also gathered information from mental health graduate students or psychiatry residents who volunteered to 'staff' the camp.

**Research methods:** Research methods were mainly quantitative or mixed methods. Only one study used a control group<sup>6</sup>.



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**Outcomes:** Various outcomes were measured, including carer burden and stress. Studies also examined the impact of respite programmes on the number of inpatient days and the cognitive and physical functioning of care recipients.

**Evidence relating to effectiveness:** The three studies of institutional respite for carers of people with dementia did not indicate any significant effectiveness beyond some decrease in perceived carer burden<sup>6</sup> and an increase in positive feelings for some carers<sup>182</sup>. It is the negative aspects of institutional respite that are perhaps of more interest; for example, one study<sup>6</sup> reported worse relationships between some carers and care recipients on return and another<sup>182</sup> identified the possibility that institutional respite could indicate the first step towards carers seeking permanent residential care for the person supported. The degenerative nature of dementia-related illnesses makes the study of respite more complex where the dynamic relationship between opportunities for a break and subsequent relationships between carer and care recipient require further examination.

For carers of people with other serious mental illnesses, there is little evidence regarding the effectiveness of institutional respite. One of the studies found some evidence to suggest that planned residential respite could reduce overall number of rehospitalisation days<sup>189</sup>, while the other reported positive evaluations from carers and staff of annual respite camps<sup>4</sup>.

Overall there is little evidence regarding the effectiveness of institutional respite, particularly with regard to individuals suffering from illnesses other than dementia. Even here the evidence is mixed, suggesting that there are potentially positive and negative outcomes of institutional respite care.

**Economic aspects:** No economic study addressing institutional respite was identified.

**UK studies:** The study of the UK night nursing service evaluated the first 18 months of operation. Care recipients were collected in a 'sitting' ambulance with a nurse escort in the evening and returned home the following morning.

**Gaps in the research:** There is clearly a need for more research regarding the effectiveness of all institutional respite services. Within this, there is a place for more experimental work to compare different types of institutional respite along various dimensions, such as: different kinds of provision for care recipients; different lengths of time in respite; differences between 'as-needed' respite and 'pre-planned' respite. In each case, the effect of these on carers requires further investigation. Generally, there is a need for more understanding about the relationship between respite and permanent institutionalisation, enhanced coping behaviours, and enhanced medication compliance.

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### **Mixed respite care services (N = 15)**

<b>Study identification code numbers</b>	7, 9, 10, 39, 64, 81, 85, 86, 93, 153, 154, 157, 201, 229, 234
<i>(see Table 4 in Appendix 4)</i>	
<b>Patient group</b>	AD/dementia (13), schizophrenia (0), other serious mental illness (2).
<b>Setting</b>	USA (9), UK (5), Canada (1)
<b>Main measures of effectiveness</b>	Standard outcome measures (7) Programme evaluation/satisfaction surveys (6)

**Interventions:** Six of the studies looked at large-scale respite demonstration programmes in the USA. Two articles<sup>85, 154</sup> reported on the respite programme established in the state of Maryland for carers of people with Alzheimer's disease. A further two articles<sup>7, 64</sup> reported on the Michigan Model Projects Specialised Respite Care Programme, and the remaining two papers<sup>10, 229</sup> looked at Philadelphia's respite demonstration programme. Generally speaking, these programmes offered one or more of the following forms of respite: adult day care, in-home respite care and/or short-stay institutional respite in a nursing or residential home.

The remaining studies were similarly of services that offered both day and overnight respite care. Some of the studies were not of individual or specific respite interventions, but instead consisted of carers' overall evaluations of the different types of respite support they had received.

**Sample sizes:** Sample sizes ranged from fairly small to very large, for instance in four studies<sup>39, 93, 153, 157</sup> there were less than 25 participants. In comparison, the studies of the large-scale US respite programmes had much larger samples. The Maryland project had a sample size of 228, comprising carers who were 'users', 'stoppers' and 'non-users'<sup>85, 154</sup>. Some 632 carers, distributed in either a treatment group or a control group, took part in the Philadelphia programme<sup>10, 229</sup>.

**Participants:** Carers participated in all the studies, but not all of them used the respite services under investigation. In one case<sup>9</sup> the sample consisted of only female carers (wives or daughters). In one UK study<sup>157</sup>, the age of participants spanned 14 to 85 years. There were more female carers than male carers in the majority of studies. Care recipients were predominantly (elderly) people with Alzheimer's disease or other form of dementia.

**Research methods:** A mixture of research methods was found: some studies were quantitative, others used individual interviews and yet others adopted a mixed-methods approach. Exceptionally, one study<sup>39</sup> involved 12 carers taking part in a focus group. Only a small number of studies used control groups and a repeated measures design. There were some comparative studies. One study<sup>9</sup> compared in-home respite services with adult day care services. Others made comparisons between users and non-users of respite care.

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**Outcomes:** The outcomes investigated included carers' subjective/objective burden and morale, well-being and physical health. The effect of respite on the person supported was also examined. Carers' perceptions of the benefits and drawbacks of respite care were examined. One article <sup>154</sup>, focusing on the relationships of race and culture to service use and outcomes, looked at utilisation and effects of respite by African American and white carers.

**Evidence relating to effectiveness:** Carers reported high satisfaction with respite services <sup>9, 10, 86</sup>; compared with adult day care, there were more positive outcomes reported by these studies. Effectiveness was reported in a number of areas, including reductions in subjective burden <sup>7, 85</sup>, increased carer morale <sup>7</sup>, and reductions in carer stress <sup>86, 93</sup>. These findings suggest that respite can produce positive outcomes for carers, although few studies examined how or why this might be the case. Contradictory evidence is presented with regard to the effect of respite on permanent institutionalisation, with one study <sup>10</sup> reporting that respite users were more likely to maintain their relative in the community and another <sup>93</sup> reporting that respite use had no effect on long-term institutionalisation. The studies are not comparable in terms of sample or form of respite, but do suggest that further research is needed to understand the relationship between forms of respite and institutionalisation.

Some of these studies reported findings that have a bearing on specific forms of respite care. The authors of one study <sup>81</sup> reported that spouses are particularly concerned about the quality of respite and prefer in-home care to adult day care. They also reported that spouses are more likely to seek respite that provides benefits to the care recipient. Other researchers <sup>9</sup> reported that users of home-care respite have lower numbers of care-giving hours compared with users of adult day care where no reduction in hours caring was found. They suggest this may be because relatives spend time preparing for adult day care in ways that are not necessary for in-home respite. This finding suggests that the subtle differences between forms of respite may have implications for overall effectiveness.

The lack of comparability among these studies makes it difficult to assess overall effectiveness. Clearly there are contradictory messages emanating from research regarding the potential benefits for carers deriving from respite care services, although carer satisfaction from these interventions remains high.

**Economic aspects:** One economic study <sup>201</sup> assessed mixed-respite care services. The study was designed as a case series study with matched controls and aimed to evaluate a Family Support Unit (FSU) in the north-east of England. Through the provision of tailored day and residential respite care, the unit's goal was to enable patients to remain at home as long as possible. Thirty-five elderly mentally infirm patients visiting the FSU formed the intervention group; of these, 24 had carers available for interview. The costs of care and support received from public and private sectors were estimated for both groups. On average, patients in the intervention group were institutionalised almost six months later than control patients and a higher proportion of carers in the intervention group reported a sense of freedom or relaxation compared with controls. The difference in the rate of

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institutionalisation between the groups meant that the FSU was cost-saving, but only when a broad cost perspective was adopted. The authors emphasised that cost savings would not accrue to the local authority that was jointly responsible for funding the unit.

**UK studies:** The five UK studies<sup>39, 86, 157, 201, 234</sup> used mainly qualitative methods. One piece of research<sup>39</sup> involved a focus group comprising 12 carers who were either current or recent users of respite services in an inner London health authority. In a second study set<sup>157</sup>, in London, 23 carers were interviewed about their experiences of respite care. This study deliberately used a qualitative methodology to find out about the benefits and problems of respite care in order to complement and add to the existing work based on statistical analysis and standard measures. The remaining three studies evaluated units providing day and night care for elderly mentally infirm people in Northamptonshire<sup>86</sup>, north-east England<sup>201</sup> and Kent<sup>234</sup>.

**Gaps in the research:** There is a need for more comparative work about respite services and their effectiveness for different subgroups of carers. Existing evidence suggests that non-spouse carers who work have needs and expectations of respite that are different from those of spouse carers who are not working<sup>81</sup> and these findings require further exploration. The effect of respite on carer-patient relationships is also worthy of further research since mixed evidence is presented regarding the long-term implications of respite use.

A systematic review of respite by McNally *et al.* (1999) identified the need for a more 'carer-centred' approach to evaluation and provision of services, to take account of factors such as the relationship of the carer to the patient, the activities that carers undertake during periods of respite, and the effect of respite on care recipients. The studies reported in this review would suggest that little has been achieved since that report to fill these gaps in our understanding or knowledge.

### ***4.2 Educational interventions (N = 73)***

#### **Education (N = 29)**

<b>Study identification code numbers</b>	14, 18, 19, 20, 30, 43, 49, 57, 72, 75, 76, 80, 102, 113, 120, 125, 131, 140, 145, 158, 159, 160, 162, 164, 168, 272, 285, 286, 287
<b>(see Table 5 in Appendix 4)</b>	
<b>Care recipient group</b>	AD and dementia (17), schizophrenia (5), other serious mental illness (7)
<b>Setting</b>	USA (17), UK (8), Italy (2), Canada (1), Ireland (1)
<b>Main measures of effectiveness</b>	Standard outcome measures (17), programme evaluation/satisfaction surveys (9)

**Interventions:** Of the 29 articles retrieved, two<sup>102, 272</sup> reported on the same (UK) intervention. Educational programmes were typically short term, varying in lengths from just 90-minute meetings to up to 12 weekly sessions of two to three hours each. Some were lead by professionals; others by carers or other

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family members; and yet others by both professionals and carers. Two studies focused on the roles of community psychiatric nurses <sup>159, 164</sup> in the provision of education and information to carers and relatives, and another on the role of occupational therapists <sup>75</sup>.

The content of educational programmes varied, but generally speaking included standardised information about the specific disease, community resources and services available, communication skills, coping strategies, problem-solving techniques and patient-management skills. One workshop <sup>158</sup> focused specifically on legal and financial matters. There was a pilot study <sup>18</sup> of the effectiveness of the 'Family-to-Family Education Program', a programme developed by the US organisation, the National Alliance for the Mentally Ill. This was formerly the 'Journey of Hope Education Program', which had previously been evaluated and is also included in the review <sup>72</sup>. While the majority of interventions were delivered in a group situation, in some cases information was presented in the home setting to carer and patient together.

**Sample sizes:** The majority of studies had sample sizes of 50 carers or fewer. Exceptionally, there were two large-scale surveys of educational interventions which generated responses from 370 <sup>30</sup> and 424 <sup>72</sup> individuals respectively.

**Participants:** Some educational interventions were aimed at primary carers. Study participants comprised mainly female carers rather than male. Where given, ages covered a wide range from 16 years <sup>14</sup> to carers in their 80s <sup>140, 158, 159, 160</sup> and even 90 in one case <sup>125</sup>. One educational intervention <sup>125</sup> was for patients in the early stages of Alzheimer's disease; another was for people with Huntington's disease <sup>168</sup>. One study <sup>75</sup> collected information from four occupational therapists only.

**Research methods:** The majority of studies were quantitative. Some, but not all, used repeated measures. Just less than half had a control group. A very small number of studies undertook short-term follow-up at three or six months. There were some comparison studies. For instance, researchers compared three different ways to deliver information to relatives of people with schizophrenia: in a group, by post and by video <sup>102, 272</sup>. Another study <sup>160</sup> looked at an educational support group and an Alzheimer's Association support group.

**Outcomes:** The outcomes examined varied, but tended to concentrate on psychological distress, coping skills, quality of life, well-being and levels of knowledge of disease. Programme evaluations were also undertaken. The role and effectiveness of specialist professionals in providing education and support were examined.

**Evidence relating to effectiveness:** A range of positive outcomes feature in the reports of education strategies for carers of people with both dementia-related illnesses and schizophrenia. In the main, these relate to improved knowledge about the illness and reductions in negative aspects of caring such as stress, anxiety and concern for the care recipient. These studies do provide evidence to suggest that educational interventions are successful in providing knowledge that is maintained over time <sup>272, 164, 287</sup>. However, there is less evidence to support the claim that increasing knowledge leads to reductions in stress or burden among carers. Although one study <sup>272</sup> found decreases in

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stress and increased optimism regarding family role alongside increased knowledge at post-treatment stage, only knowledge was retained at six-month follow-up. Similarly, another study<sup>168</sup> found that only knowledge was retained at follow-up and other positive outcomes were not. This ambiguity about the nature of causality between increased knowledge and negative aspects of caring has led some to suggest that it is change in patients' behaviour, rather than knowledge *per se*, that affects levels of carer stress<sup>120, 145</sup>.

Thus, while there is evidence to support the view that providing education for carers has immediate positive outcomes, and that knowledge is retained over time, there is less evidence regarding the impact of that knowledge on other aspects of carer experience. It may be concluded that education as information is an important supplement to other interventions, but may be inadequate as a sole response to potential carer problems.

**Economic aspects:** No economic study addressing this category of education was identified.

**UK studies:** Altogether, there were eight papers<sup>49, 102, 159, 162, 164, 272, 286, 287</sup> reporting on seven different interventions. Two studies examined educational support for carers of people with dementia<sup>159, 162</sup>, while the remainder focused on services for carers of people with schizophrenia and/or mental illness. Generally, they were small-scale interventions, in the sense that their time duration was short and/or the numbers involved were generally low. One intervention, the focus of two separate articles<sup>102, 272</sup>, compared three different methods to deliver educational interventions (see above). Two unrelated studies<sup>159, 164</sup> looked at the role and impact of community psychiatric nurses in providing education and support to relatives. One study<sup>159</sup> used a combination of both quantitative and qualitative methods. The rest all adopted a quantitative research design. As well as pre-test and post-test measures, some had follow-up at six months.

**Gaps in the research:** Key questions regarding the delivery of education are not addressed in this literature, namely when education is most effective in terms of carer or mental illness trajectory, and which components of education programmes are most effective, if indeed these can easily be separated. More generally, the need to establish greater understanding regarding the causal relationship between education and carer burden and stress remains important.

### **Training (N = 21)**

<b>Study identification code numbers</b> (see Table 6 in Appendix 4)	17, 59, 66, 71, 73, 88, 90, 96, 126, 129, 135, 144, 147, 151, 155, 179, 180, 184, 188, 196, 273
<b>Care recipient group</b>	AD and dementia (21), schizophrenia (0), other serious mental illnesses (0)
<b>Setting</b>	USA (12), Australia (5), Canada (2), UK (2)
<b>Main measures of effectiveness</b>	Standard outcomes measures (18), programme evaluation/satisfaction surveys (4)

**Interventions:** There were 21 relevant articles. Of these, four papers<sup>96, 144, 196, 273</sup> related to the same study conducted in Australia. This intervention comprised a structured, residential, intensive 10-day training programme for

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carers, boosted by follow-ups and telephone conferences over 12 months. All patients received a 10-day structured memory retraining and activity programme. Two other articles<sup>129, 188</sup> featured the same intervention, a training programme designed to improve carers' communication skills with the person supported. Other interventions included a stress management programme<sup>59</sup>, a relaxation training programme<sup>17</sup> and treatment to reduce sleep problems<sup>126</sup>. Programmes tended to be short, the longest lasting for 12 weeks<sup>73</sup>. However, some participants in one eight-hour training programme (spread over four weeks) did receive booster follow-up training at four months, eight months and 11 months after entry to the study<sup>188</sup>.

Some eight<sup>71, 90, 135, 147, 151, 179, 180, 184</sup> of the training interventions could be described as 'dual target' (Silliman *et al.*, 1990). They tended to involve the implementation of cognitive stimulation programmes in order to disrupt the trajectory of decline in patients with Alzheimer's disease or other form of dementia, and at the same time improve familial quality of life. One study<sup>180</sup> evaluated the impact of a gentle hand treatment for dementia patients using three essential oils, from the point of view of both patients and carers.

**Sample sizes:** Sample sizes varied, and for the more straightforward training programmes generally comprised fewer than 40 participants. One exception was the Australian training programme<sup>96; 144; 196; 273</sup>, which involved 96 patient–carer couples allocated to one of three treatment conditions. Some of the dual-target interventions also had larger sample sizes; for example, there were four studies<sup>90; 135; 151; 179</sup> with 65 or more carer–patient dyads.

**Participants:** Training interventions were often aimed at main and/or spouse carers. One stress management programme<sup>59</sup> was for carers who had identified moderate to high levels of stress. More often than not, carer samples consisted of women rather than men. There were a number of interventions focusing specifically on patients at particular stages in the disease trajectory, for instance, early to mid-stage Alzheimer's disease<sup>129, 188</sup> or mild to moderate dementia<sup>196, 273</sup>. Some interventions involved carer–patient dyads. Exceptionally, data were also collected from day care staff in one study<sup>180</sup>.

**Research methods:** The methods adopted in the majority of studies were quantitative. One action research study<sup>180</sup> was a collaborative piece of work where carers and day care staff participated with the researchers in choosing, designing, developing and evaluating the (hand treatment) programme.

More than half the studies used control groups, and most adopted a repeated measures design. The Australian research was longitudinal and conducted an annual follow-up of up to eight years<sup>144</sup>. There were a number of comparative studies. For example, one study<sup>73</sup> compared the effects of two different training interventions: a behaviour management programme and a social skills programme. Another<sup>66</sup> looked at a skills training cognitive-behavioural group intervention, and compared this to a support group that emphasised information-giving and social exchanges between participants.

**Outcomes:** Studies examined the effects of the interventions by measuring a range of outcomes, including carer burden, self-esteem, depression, hassles and asking for help. The dual target interventions looked at outcomes related

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to the functional status and behavioural disturbances of patients. The Australian study used survival analysis to look at the significance of carer education and training on nursing home admission and death in relation to patients with dementia

**Evidence relating to effectiveness:** The range of types of training offered to carers makes it difficult to assess overall effectiveness of this approach. A number of studies have reported positive benefits of behaviour training for carers, including reductions in carer stress <sup>273</sup>, delay and reductions in institutionalisation <sup>96; 144; 273</sup>, improved quality of life <sup>184</sup>, and reduced carer depression <sup>90; 151</sup>. However, some researchers <sup>147</sup> found that although improved carer mental health and reductions in the behavioural difficulties of patients after behaviour training occurred, it was not possible to identify in what direction these were related. Furthermore, others <sup>66</sup> found no significant differences between the outcomes for carers of cognitive behaviour skills training and information giving, suggesting that the specific components of interventions require more careful evaluation.

Other forms of training, such as communication skills training <sup>129; 188</sup>, relaxation techniques <sup>17</sup> and stress management <sup>59</sup>, have also been found to have positive effects on carers, suggesting that training in specific techniques focused on particular aspects of carer experience may be beneficial.

There is clearly a body of evidence to support the development of training services for carers, and to continue evaluation of innovative and developmental techniques. The development and use of behavioural training that has the potential to be effective for both carers and patients requires further consideration.

**Economic aspects:** One of the four papers <sup>196</sup> relating to the Australian intervention assessed the economic impact of training. As stated earlier, the controlled before-and-after study evaluated the impact of an intensive 10-day programme (delivered directly for one group and after a wait of six months for another group) with no carer support. Patients in the control group received a memory retraining programme. The 39-month follow up assessment found significantly lower rates of institutionalisation in both the intervention groups compared with the control and the authors concluded that the intervention was cost-saving.

**UK studies:** There were two studies set in the UK <sup>7; 147</sup>. One <sup>7</sup> evaluated a structured stress management programme followed by seven carers of people with dementia. The second study <sup>147</sup> reported on an intervention designed to improve carers' ability to cope and manage behavioural disturbances in their relatives.

**Gaps in the research:** The types of behavioural training provided in these studies require replication and further evaluation. There is little evidence to support any particular style of intervention over another, or any evidence to help assess when training can be most effective. The time delay in training and potential benefits also needs to be considered, since it is possible that these kinds of interventions require 'practice' and that positive outcomes may not be seen for some time after the training has been given (see, for example, <sup>127</sup>). All



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the examples of training reported here were for carers of people with dementia-related illnesses and therefore the efficacy of such programmes for other mental illnesses requires further investigation. For carers of people with degenerative illnesses such as dementia, there is also a need to understand how training needs might change over time and how skills can be updated, and what the effects of this might be on patients as well as carers.

### **Psychoeducational interventions (N = 23)**

<b>Study identification code numbers</b>	2, 5, 16, 21, 22, 23, 48, 54, 55, 56, 58, 68, 69, 70, 79, 87, 104, 105, 106, 107, 141, 148, 174
<i>(see Table 7 in Appendix 4)</i>	
<b>Care recipient group</b>	AD and dementia (11), schizophrenia (8), other serious mental illness (4)
<b>Setting</b>	USA (14), Australia (3), Japan (2), UK (1), Germany (1), Netherlands (1), China (1)
<b>Main measures of effectiveness</b>	Standard outcome measures (18), programme evaluation/satisfaction surveys (9)

**Interventions:** The literature search produced 24 relevant articles. There were three separate occurrences of two papers<sup>16/48, 70/79, 104/106</sup> being written about the same intervention, in other words 24 articles had been written about 21 different interventions. Generally, the psychoeducational interventions sought to: provide carers with information about the specific disease, and how the patient, the main carer, and the family as a whole might be affected; enhance carers' practical skills; strengthen feelings of confidence and belief about coping; and improve family communication and co-operation. A minority included patients as well as carers. Some interventions were short, for instance day-long workshops, whereas others took place on a weekly basis – for example, once every two weeks for nine months. One psychoeducational group<sup>58</sup> was specifically for spouses (of people with serious mental illness), and another<sup>58</sup> was directed at male carers (of patients with Alzheimer's disease). A third<sup>70, 79</sup> targeted spouse carers of people in the early stages of Alzheimer's disease.

**Sample sizes:** Sample sizes varied widely. For example, there were 22 or fewer participants in seven of the studies<sup>2; 21; 22; 54; 55; 58; 70</sup>. On the other hand, three studies<sup>5; 104; 106</sup> had over 220 participants. The completed sample in a fourth study<sup>69</sup>, examining a two-year project implemented in two cities in China, included 682 cases in the treatment group and 366 cases in the control group.

**Participants:** As well as primary carers, interventions focused on other specific groups of carers: parents<sup>2</sup>, spouses<sup>54; 70; 79</sup>, female carers<sup>56</sup>, and male carers<sup>58</sup>. Study samples often comprised more female carers than male carers; it was not unusual for carers to be in their 80s. Two interventions were for people with schizophrenia under the age of 40<sup>2, 107</sup>, two were for people with bipolar disorder<sup>21, 23</sup> and one was for elderly people with recurrent major depression. In some cases, participants were carer–patient dyads or families. The one UK study<sup>87</sup> was exceptional in that it collected data not only from carers but also from professionals (see below).

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**Research methods:** All the studies apart from three <sup>58; 87; 148</sup> used quantitative methods. About one-third of studies used control groups; three-quarters conducted pre- and post-tests. A number had follow-ups, in one case of up to two years <sup>69</sup>. There were some comparison studies; for example, one study compared two models of brief psychosocial education <sup>106</sup>.

**Outcomes:** Outcomes measured were wide-ranging, and included carers' knowledge, psychological stress, burden, satisfaction with life, well-being, physical health and self-efficacy. Some of the studies asked participants to undertake a programme evaluation.

**Evidence relating to effectiveness:** Evidence regarding the effectiveness of psychoeducational approaches for carers is diverse and contradictory. On the whole, this is because of the varying components that make up the programmes so that it is difficult to identify which element might be particularly effective. In relation to interventions for carers of people with dementia, for example, one study <sup>148</sup> found no effect on stress, burden, satisfaction with life, well-being or knowledge compared with control group, leading the researchers to conclude that interventions should be tailored to individual needs; another <sup>70</sup> found an increase in preparedness for carer role, increase in competence, increased use of positive coping strategies and a reduction in perceived strain among carers which led the researchers to conclude that intervention at an early stage in disease progression could improve carer well-being and ability to cope. These two examples illustrate the importance of being able to match interventions to carer needs at specific stages of a mental illness. Overall there is some evidence to support the use of psychoeducational approaches for carers of people with dementia but the mechanisms through which positive outcomes are achieved are not well understood (48).

Evidence regarding the effectiveness of psychoeducational interventions with carers of people with schizophrenia are similarly mixed, although three of the five studies reported no significant improvements <sup>105; 107; 174</sup>. Only one study <sup>69</sup> reported positive outcomes for a two-year group programme which reported lower levels of burden, improved health status and increased knowledge among participants. The mixed results suggest that different kinds of programmes will have different outcomes and that evidence is limited regarding which components are most effective (see <sup>107</sup>).

Similarly mixed findings are reported by studies that evaluated interventions for carers of people with serious mental illnesses (which might include schizophrenia and bipolar disorders), although questions are raised regarding the maintenance of improvements over time. Researchers <sup>106</sup> suggest that education strategies can provide a shortcut to processes of maturation in coping that happen anyway and thus no long-term improvements should be expected. Others <sup>54</sup>, however, found that increased knowledge, improved coping strategies, reduced distress and reductions in negative attitudes to the ill person were maintained at one year which suggests that not only do components of psychoeducational strategies need to be understood but that what is meant by 'long-term' benefits requires further consideration.

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Overall, the numerical significance of educational and psychoeducational interventions suggests that these have gained currency in recent years. The evidence regarding their effectiveness is sometimes contradictory, although most interventions offer at least one positive outcome measure.

**Economic aspects:** No economic study addressing psychoeducational interventions was identified.

**UK studies:** There was one study<sup>87</sup> evaluating the Admiral Nurse Service in comparison with the conventional assistance provided by mental health services in the North Thames Region to people with dementia and their family carers. The researchers described the service as primarily a psychoeducational intervention, with some elements of service co-ordination.

**Gaps in the research:** Given the range and type of education interventions that have been evaluated there is a clear case to suggest that a full systematic review should be undertaken in this area. In particular, the use of psychoeducational approaches in relation to schizophrenia and other serious mental illnesses ought to be undertaken.

The clear difficulty with regard to research in this area relates to the multiple components that any intervention might embrace. Not only does this make evaluation difficult but it also raises questions regarding the possible transferability of interventions between settings and groups of carers.

### ***4.3 Family interventions (N = 20)***

<b>Study identification code numbers</b>	40, 60, 92, 99, 101, 103, 108, 109, 110, 112, 116, 137, 165, 172, 261, 263, 271, 274, 275, 289
<i>(see Table 8 in Appendix 4)</i>	
<b>Care recipient group</b>	AD and dementia (1), schizophrenia (13), other serious mental illness (6)
<b>Setting</b>	UK (13), USA (4), Netherlands (1), China (1), Malaysia (1)
<b>Main measures of effectiveness</b>	Standard outcomes measures (16), programme evaluation/satisfaction surveys (1)

**Interventions:** Of the 20 articles, there were four instances of two papers 40/289, 101/109, 110/275, 112/137 having been written about the same family intervention service. In other words, 20 articles discussed 16 interventions. Most of the articles focused on interventions drawing on family therapy models. The interventions varied, but tended to include components focusing on family education about the specific disease, training in problem-solving and/or communication skills, and the development of coping strategies. Some intervention packages also included relatives' groups.

One of the US studies<sup>60</sup> evaluated a particular family-based therapy called Structural Ecosystems Therapy (SET). The aim of the SET intervention was to improve carers' interactions within their social ecosystem (including family, community, service providers) to increase the extent to which their emotional, social and instrumental needs were met and, in turn, improve psychological adjustment. The Chinese study<sup>108</sup> evaluated a newly developed comprehensive

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intervention for families, once it became clear that approaches used in the West such as family therapy and behavioural treatments made assumptions that did not hold true in China.

Studies from the UK are discussed in more detail at the end of this section.

**Sample sizes:** Three studies <sup>112; 116; 172</sup> had study samples of 31 or fewer. At the other extreme, there was one study <sup>60</sup> with 224 participants.

**Participants:** As with other types of interventions, carer participants were mainly women. One US study <sup>60</sup> of family-based therapy was aimed at white American and Cuban American primary carers. Similarly, a UK study <sup>271</sup> was designed to appeal specifically to ethnic minority carers. The majority of interventions were for patients with schizophrenia or other mental illness conditions. In one study <sup>92</sup>, data were also collected from professionals, namely family support workers (FSWs) and co-professionals from the FSW's multidisciplinary teams.

**Research methods:** The majority of studies used quantitative methods, just two <sup>112; 172</sup> were qualitative, and one <sup>92</sup> used a mixed methodology. Half had control groups. Most studies used a repeated measures design, with follow-ups between 12 months and two years. There were a small number of comparative studies. The SET study <sup>60</sup>, for example, assigned carers to one of three conditions: SET, SET enhanced with a computer-integrated telephone system, and a minimal-contact telephone support control group.

**Outcomes:** The outcomes that researchers focused on for carers and/or relatives included levels of expressed emotion, burden, coping, and distress. Care recipient relapse rates and the functioning of the whole family unit were also assessed.

**Evidence relating to effectiveness:** All but one study <sup>60</sup> deals with the effectiveness of family therapy for relatives of people with schizophrenia or serious mental illnesses other than dementia. A key outcome measure used in these studies is how far family therapy can reduce relapse. There is evidence to suggest that family therapy can be effective in reducing relapse rates <sup>101; 108; 109; 261; 289</sup>, although one study found no effect on 'expressed emotion' (EE) or relapse <sup>99</sup>.

Other aspects of the effectiveness of family therapy have also been identified by these studies, including: improvements in patient behaviour <sup>116; 165</sup>, improvements in family relationships <sup>110; 172; 275</sup> and reductions in family burden <sup>92; 103; 108; 165</sup>.

Only two studies have considered the differences between services or components of services in relation to potential effectiveness. One <sup>165</sup> reports that the outcomes from Culturally Modified Family Therapy may be sustained over time compared with Behavioural Family Therapy although both were found to be effective across various dimensions. Other researchers <sup>112</sup> have suggested that it is the non-specific aspects of family therapy such as emotional support, backup and reassurance that are more important to families than specific aspects of behaviour change and skills.

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Overall, there is considerable evidence to support the effectiveness of family therapy in reducing relapse rates among people with schizophrenia compared with other interventions considered in this review, although there is less evidence that any particular component or model of family therapy is more efficacious than another.

**Economic aspects:** Three studies<sup>261; 263; 274</sup> included an economic evaluation of family interventions. Two studies<sup>261; 274</sup> targeted support at families of patients with schizophrenia and one<sup>263</sup> addressed patients with severe mental illness and concurrent mild mental retardation. All studies enrolled fewer than 75 patients. In the US study<sup>274</sup>, patients with schizophrenia were randomised to either family management or to individualised supportive management, the latter representing usual care. Both groups also received pharmacotherapy and assertive case management. The UK study<sup>261</sup>, which was observational in design, compared a range of educational and behavioural family interventions with routine care, with groups allocated on the basis of family levels of EE. This study also targeted support at families of patients with schizophrenia. Patients with severe mental illness and concurrent mild mental retardation were the subjects of the Dutch study<sup>263</sup>. In this trial, patients were randomly assigned to either specialised inpatient treatment or to outreach treatment at home.

Positive economic benefits were reported by all three studies. The UK study<sup>261</sup> found the intervention to be cost-saving, mainly due to differences in the between-group rate of hospitalisation. The US study<sup>274</sup> reported the intervention to be cost-effective, measuring effectiveness as a composite index of patient psychiatric morbidity, patient social functioning and family functioning. The Dutch study<sup>263</sup> reported that the treatment costs for the outreach group were lower than those for the hospital group, but found no difference in measures of carer burden, thus concluding that the intervention was cost-effective.

**UK studies:** Five of the 13 UK research reports<sup>101; 103; 109; 110; 275</sup> were published in 1990 or earlier. These five were all studies of family therapy programmes. For example, two articles<sup>101; 109</sup> reported the results relating to relatives' EE and relapse rates of a follow-up at nine months, and then two years, of a study where 12 families (including patients) were assigned to family therapy and 11 to a relatives' group (excluding patients). In addition, a short (two sessions) educational programme was given to all relatives taking part in the study in their home. Another intervention that was reported<sup>110; 275</sup> involved an interactive education session at home, followed by a monthly relatives' group. This intervention aimed to reduce components of EE and to alleviate burden.

More recent work comprised two articles<sup>112; 137</sup> reporting on a service called STEP. This programme had been operating in a British district mental health service for a number of years and implemented family intervention approaches in schizophrenia within a routine clinical service rather than as part of a specially funded research project. Two therapists visited each patient and family at home on a regular basis. After completion of an educational package, the therapists jointly completed an assessment of the family's needs. This intervention focused on improving the family's problem-solving and

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communication skills; family members were encouraged to set goals to promote the patient's active rehabilitation.

Other studies have also looked at the effectiveness of family interventions in routine service settings. For instance, two articles <sup>40; 289</sup> reported on the same needs-based family intervention service where patients in both the treatment and control groups were allocated a FSW from the voluntary organisation Making Space, located in the north-west of England. Patients and carers in the treatment group were offered specific interventions determined by a systematic assessment of carer needs for psychosocial interventions. Another study <sup>92</sup> set out to specifically evaluate the impact of the FSW service developed by Making Space on the quality of life of carers of schizophrenia sufferers.

**Gaps in the research:** Only one study <sup>60</sup> examined the use of family therapy for carers of people with dementia. Their finding that family therapy might be a way to increase social support warrants further investigation, as do questions regarding the transferability of family therapy interventions to carers of people with other types of mental illness. There is also a need for greater consideration to be given to the components of family therapy over time and also to the differences between service types, as suggested above. It may also be the case that some research should consider the way in which family therapy can be tailored to individual/family needs within the context of a complete package of care.

### ***4.4 Mutual support and social activity groups (N = 18)***

<b>Study identification code numbers</b>	3, 8, 11, 12, 13, 15, 42, 44, 51, 65, 82, 89, 91, 122, 123, 128, 161, 173
<i>(see Table 9 in Appendix 4)</i>	
<b>Care recipient group</b>	AD and dementia (12), schizophrenia (2), other serious mental illness (4)
<b>Setting</b>	USA (12), Australia (2), Canada (2), UK (1), Netherlands (1)
<b>Main measures of effectiveness</b>	Standard outcomes measures (12), programme evaluation/satisfaction surveys (8)

**Interventions:** Studies in this category covered support groups for carers and other family members, with the exception of just one article from the USA reporting on the benefits and costs for members of a state-wide self-help group <sup>8</sup>. The two Canadian papers <sup>11; 12</sup> discussed the same support group; so, too, did two US articles <sup>65; 123</sup>.

Support groups in some studies set in the USA were affiliated with specific organisations, such as the Alzheimer's Association <sup>44</sup> and the National Alliance for the Mentally Ill <sup>13</sup>. Others were linked into community health or social services organisations – for instance, day hospitals or residential homes. Some support groups were led solely by peers or carers, others by professionals and yet others by a professional–peer team. Some, but not all, of the support groups followed specially designed programmes. A number of support groups

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were time-limited; in contrast, others were made available to carers for as long as they were needed.

**Sample sizes:** The smallest sample size was 10 <sup>161</sup>, and the largest was 348 <sup>3</sup>. Three-quarters had sample sizes of over 50.

**Participants:** Some, but not all, support groups were aimed at the main carer. Generally, the majority of carer participants were women, in one case <sup>11/12</sup> ranging from 30 to 90 years of age. Care recipients were mainly suffering from Alzheimer's disease or other form of dementia. One US study <sup>8</sup> was of people with schizophrenia and bipolar disorders. Support group leaders were included in one study <sup>3</sup>.

**Research methods:** While the majority of studies used quantitative methods, few were designed as randomised controlled trials. Some were postal surveys intended to gather data to allow comparisons to be made between members and non-members of support groups. The shorter time-limited support group programmes lasted eight or ten weeks. Others were unlimited, and attendance was up to the individual carer. Very few studies conducted pre- and post-intervention tests, together with longer term follow-up. Exceptionally, one study was a retrospective analysis of the effects of carer support groups over an eight-year period <sup>51</sup>.

**Outcomes:** A wide range of outcome and measurement tools was utilised. These included measures of carer psychological well-being, burden, social support, perceived benefits of taking part in a support group and 'survival' of the care-giving experience (to assess the impact of support group participation on the institutionalisation of the patient).

**Evidence relating to effectiveness:** Toseland and Rossiter's (1989) literature review of support groups concluded that no clear link could be established between support groups and carer experience across a range of outcome measures. In the period since then, none of the studies using standard outcome measures reported any findings to contradict this conclusion, with the exception of one study <sup>13</sup> of members of the Alliance for the Mentally Ill that reported lower levels of carer burden compared with non-members. In contrast, there have been a number of qualitative studies of support groups that reveal the positive aspects of group involvement, such as emotional support, importance of sharing experience, and helping carers to cope with their situation and develop a more positive outlook <sup>89; 91; 123; 161</sup>.

Some studies have addressed the question of who might benefit from support groups. Reported findings suggest that carers in most distress <sup>51</sup> and carers most dissatisfied with their role <sup>91</sup> have most to gain from support groups, while members of self-help groups in the USA were more likely to be white, highly educated and higher up the socioeconomic scale <sup>8</sup>. One of the studies of support groups for carers of people with schizophrenia concluded that support groups needed to be aware of how carers' needs changed over time and how these shifts might affect support group effectiveness <sup>173</sup>. It might be argued that this conclusion is relevant to all forms of support groups for carers of people with mental health problems.

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In sum, there does not appear to be any conclusive evidence regarding the effectiveness of support groups for carers of people with mental health problems. Although qualitative work has identified some of the positive aspects of group involvement, and reported satisfaction with such services is high, findings across a range of standard outcome measures do not indicate any significant change in carer experience.

**Economic aspects:** No study addressing the economic aspects of either mutual support or social activity groups was identified.

**UK studies:** There was just one UK study in this category <sup>161</sup>. This was a questionnaire evaluation of a small support group for relatives of people with chronic mental illness living in the community.

**Gaps in the research:** The gap between standardised outcomes and levels of satisfaction with support groups suggests that there is need for greater understanding of the dynamics of group involvement for carers. In particular, the different content of these groups requires closer examination, with perhaps some experimental work with different subgroups of carers. Evidence is weak in terms of understanding the point at which support groups might help carers and the preventive elements of support groups have not been studied. Two areas of interest have emerged, however. First, there is some support for the view that a multi-functional support group could be devised that could embrace the 'progression' that carers and their relatives experience that might overcome the problem that highly focused support groups lose their efficacy for some carers over time. Secondly, the study <sup>89</sup> that was based on alternative models of carer stress using 'affiliated-individuation' theories reported more positive outcomes for carers <sup>89</sup> than those based on measuring burden, distress etc. on standard measures.

These findings suggest that research needs to adopt a more dynamic and theoretical approach to support groups and that existing outcome measures may be inadequate. More attention should be paid to the qualitative aspects of support group participation and the needs of different carers dealing with different stages of mental illness, and more experimentation with different forms of support groups needs to be undertaken.

### ***4.5 Counselling (N = 9)***

<b>Study identification code numbers</b>	45, 46, 47, 67, 74, 95, 115, 207, 249
<b>( see Table 10 in Appendix 4 )</b>	
<b>Care recipient group</b>	AD and dementia (7), schizophrenia (1), other serious mental illness (1)
<b>Setting</b>	USA (6), UK (1), Australia (1), Canada (1)
<b>Main measures of effectiveness</b>	Standard outcomes measures (9), programme evaluation/satisfaction surveys (1)

**Interventions:** Of the nine articles focusing on counselling interventions for carers, three papers <sup>45; 46; 47</sup> were about the same counselling programme implemented in the USA. This particular programme included individual and



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family counselling, the continuous availability of ad hoc counselling as well as support group participation. Other programmes also had two or more major components – for instance, education, the development of coping strategies, or problem solving. Some of the programmes implemented features of particular models of stress management models or problem-solving therapy. Counselling in some studies took place in the home in the absence of the patient.

**Sample sizes:** Only two studies <sup>115; 207</sup> had fewer than 45 participants. The study sample in the largest inquiry <sup>45; 46; 47</sup> totalled 206 carers, divided equally between the treatment and control group.

**Participants:** One of the interventions <sup>45/46/47</sup> focused specifically on spouse carers; participants were mainly aged 60 and above. The majority were for people with Alzheimer's disease or other form of dementia.

**Research methods:** All the studies used quantitative methods, involving pre- and post-test measures. The majority used a control group for comparison. There were some longitudinal studies assessing the effects over time of the intervention. In one piece of research <sup>45; 46; 47</sup>, carers were followed for as long as patients were still alive, which meant up to eight years' regular follow-up in some cases. One paper <sup>67</sup> documented a re-analysis of data from a previously reported intervention study comparing individual and family counselling with support groups using the method of prediction analysis.

**Outcomes:** A range of outcomes was investigated. These included carer stress, burden, depression, knowledge and health as well as the (long-term) effectiveness of the intervention in postponing or preventing nursing home placement.

**Evidence relating to effectiveness:** The range of outcome measures and lack of comparability across studies make it difficult to identify any clear messages regarding the effectiveness of counselling for carers of people with mental health problems. Two studies report that counselling had no effect on carer burden <sup>95; 249</sup> compared with control groups. The effect of counselling on psychiatric symptoms among carers is mixed. Researchers <sup>95; 249</sup> report no effect on psychiatric symptoms or psychological distress respectively. Others <sup>45</sup> report reduced depression among carers using counselling services, and yet others <sup>67</sup> found counselling to be successful in reducing personal role strain. The findings do suggest that some benefits might accrue to carers undertaking counselling, although whether these benefits are significantly greater than those achieved through other kinds of interventions remains unclear.

There is some evidence that counselling for carers might delay or postpone long-term institutionalisation <sup>207</sup>, particularly during the early and middle stages of dementia <sup>46; 47</sup>.

Only one of the studies reported findings for carers other than those caring for someone with dementia, and this found no differences in outcome measures of negative aspects of care giving <sup>74</sup>.

The evidence with regard to counselling services is patchy and incomplete. Although there is no evidence to suggest counselling has negative

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consequences for carers, neither is there any evidence to suggest that on its own this form of intervention can produce significant positive effects.

**Economic aspects:** No study addressing the economics of counselling interventions was identified.

**UK studies:** The one UK study <sup>115</sup> comprised a comparative study of two different methods of counselling carers of elderly people with dementia. Carers were randomly assigned to one of the three groups: short-term emotional support; information provision; no-treatment control group. The interventions were carried out in carers' own homes over a period of 18 weeks.

**Gaps in the research:** There are clearly gaps in evidence regarding the effectiveness of counselling services for carers. However, it remains unclear how far these gaps in knowledge should be filled by studies that focus specifically on counselling and how far this form of intervention should be studied alongside 'packages of care' of which counselling is perhaps only one strand. It is therefore possible that research should engage with the ways in which counselling can enhance or add value to other forms of intervention.

### ***4.6 Telephone and computer-based services (N = 16)***

<b>Study identification code numbers</b>	25, 26, 38, 62, 63, 94, 97, 98, 133, 134, 136, 152, 170, 242, 284, 288
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*(see Table 11 in Appendix 4)*

<b>Care recipient group</b>	AD and dementia (16), schizophrenia (0), other serious mental illness (0)
<b>Setting</b>	USA (16)
<b>Main measures of effectiveness</b>	Standard outcomes measures (12), programme evaluation/satisfaction surveys (2)

**Interventions:** Some 16 articles evaluated two types of technology-based interventions: the computer (n = 10) and the telephone (n = 6).

Between 1991 and 1998, nine papers <sup>26; 94; 97; 98; 133; 134; 152; 242; 288</sup> had been published on the same intervention: ComputerLink, a specialised computer network designed to provide carers of people with Alzheimer's disease with information, communication and decision support. The Electronic Encyclopaedia function of ComputerLink included over 200 pages of information relevant to Alzheimer's disease, and was designed to help carers enhance self-care, understand illness-specific issues and promote home-based management. The communication area allowed for public and private communication among users. In the decision support module, English-language questions guided users in an analysis of a self-defined decision problem. This function was intended to enable users to focus on the values and trade-offs that may occur during difficult choices, and to make choices that best meet their own personal values.

The various articles reported a wide range of aspects of using ComputerLink. One paper <sup>288</sup> focused on the three principal functions of the system, and discussed the results obtained by using standard instruments to examine the

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effects of ComputerLink on the confidence and skill of carers in relation to decision making, and social isolation. Issues looked at in other articles included: whether ComputerLink affected carers' use of support groups for family members <sup>152</sup>; whether the use of a computer network fostered collaboration among carers, and between carers and health care professionals <sup>26</sup>; and attitudes towards, and usage of, ComputerLink <sup>98</sup>. The first ComputerLink project was designed to reach people with AIDS, and one article <sup>97</sup> compared the use patterns of people with AIDS with those of carers of people with Alzheimer's disease.

The one remaining computer-related study <sup>170</sup> analysed the content and themes contained in over 500 messages posted on a public Internet Alzheimer Mailing List, as well as patterns of use.

The telephone-based interventions that were studied provided carers with peer network support, counselling, self-help and information. Two <sup>25</sup>; <sup>62</sup> of the six papers discussed the same intervention: Care-Line, the Caregiver Phone Network for carers of Alzheimer's patients. Care-Line was a model self-help telephone programme with two components: peer telephone network, and telephone informational lectures on Alzheimer's disease. One article <sup>62</sup> concentrated on a comparison of the two different programme components and the impact of both components over time, while the other <sup>25</sup> looked at the effect of Care-Line on carers' natural supports.

**Sample sizes:** The smallest sample size comprised four women in a study <sup>136</sup> looking at the efficacy of short-term telephone counselling, and the largest was 104 <sup>38</sup>. With the exception of the comparison study, all the ComputerLink studies had a total sample of 96 carers, made up of 47 carers in the intervention group and 49 in the control group. The study <sup>170</sup> examining the Alzheimer Mailgroup analysed the contents of 532 messages.

**Participants:** A minority of interventions focused on main carers. In nearly all the studies, carer participants were predominantly women. Patient groups were people with Alzheimer's disease or other form of dementia. One study <sup>97</sup> of ComputerLink compared use patterns of carers of persons with Alzheimer's disease with use patterns of patients (people living with AIDS), and analysed the results separately.

**Research methods:** All the studies adopted quantitative methods. They varied in terms of the length of the intervention, most ranging from 12 weeks to one year. About one-quarter of the studies conducted pre- and post-intervention tests. None of the studies incorporated any longer-term follow-up.

**Outcomes:** A wide range of outcomes was investigated, including decision-making confidence and skill, carer burden, care-related strain, stress and depression. Additionally, studies looked at outcomes regarding attitudes towards the use of a computer network, the promotion of collaboration, social support, knowledge about Alzheimer's disease, and patterns and rates of usage.

**Evidence relating to effectiveness:** The authors report a range of potentially effective aspects of both computer- and telephone-based interventions,

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although overall the evidence to support the effectiveness of these remote interventions is limited. Analysis of the use of computer-based interventions suggest that these have been most widely used as a means of communication and discussion between carers<sup>26; 133; 134</sup> as well as offering carers access to information<sup>170</sup>. Evidence regarding the effectiveness of these interventions is more limited. While one study<sup>288</sup> found that care-giver confidence in decision making increased, skill in decision making did not change. Neither was ComputerLink associated with reductions in perceived social isolation. Later analysis of ComputerLink identified reduced levels of carer strain for some carers who used ComputerLink (those with more informal support and for spouse carers). The authors conclude that ComputerLink may be most effective as a supplemental source of support but that it cannot substitute for a failed informal system<sup>94</sup>.

Evidence regarding the effectiveness of telephone-based interventions is similarly limited. Where interventions such as counselling or training were provided over the telephone, authors report some effectiveness such as: decrease in depressive symptoms<sup>63</sup>; reduction in stress and burden<sup>284</sup>; and increases in life satisfaction and use of social support<sup>63</sup>. Telephone help-lines and networks appeared to have a positive impact in relation to information and social support<sup>25; 38; 62</sup>, although the long-term benefits of these are not clear, since peer telephone networks appeared to have greater effectiveness in the short term (three months) than in the longer term (six months)<sup>62</sup>.

**Economic aspects:** One study<sup>242</sup> addressed the cost implications of ComputerLink, details of which are given above. The authors found a one per cent difference in the rate of institutionalisation between the two groups over the two-year study period. As a result, the mean cost of the intervention group, which included the cost of setting up and running ComputerLink, was lower than that of the control group and the authors concluded that ComputerLink was cost-saving.

No economic analysis of telephone-based interventions was found.

**UK studies:** None of the studies reported had taken place in the UK.

**Gaps in the research:** Many authors cite the positive aspects of computer and telephone support in relation to carers living in remote geographical areas, people who are home-bound, and people who lack other forms of support locally. However, none of these groups has been the subject of research in its own right to examine the effectiveness of such services on potentially isolated carers.

Given the increasing interest in computer- and Internet-based services, there is clearly a need for research to consider the effectiveness of these kinds of services. However, this kind of research should acknowledge the different kinds of mechanisms through which computer-based interventions may be effective and examine differences between their use as a substitution for formal and informal support, as well as the ways in which they can supplement the use of existing services.

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Telephone-based interventions can take a variety of forms and more comparative work to determine what kinds of interventions are most effectively provided in this way needs to be undertaken.

### **4.7 Domiciliary care services (N = 4)**

<b>Study identification code numbers</b>	124, 130, 269, 283
<i>(see Table 12 in Appendix 4)</i>	
<b>Care recipient group</b>	AD and dementia (4)
<b>Setting</b>	UK (3), Netherlands (1)
<b>Main measures of effectiveness</b>	Standard outcomes measures (1), programme evaluation/satisfaction surveys (3)

**Interventions:** Two <sup>130; 269</sup> of the four articles documented the same intervention, an augmented domiciliary service in north-east London. Two care assistant staff were employed to provide practical and emotional help, as well as information and advice, to the principal carer. The service was tailored to individual need, and based on a comprehensive assessment by a project manager. The keynote of the service was flexibility and continuity of care to meet the changing needs of both care recipient and carer. Another study <sup>283</sup> examined the Support and Stay scheme in West Glamorgan where (unqualified) nursing assistants performed a variety of tasks, including helping care recipients with personal care tasks, checking that they were taking prescribed medication, taking them to hospital for an outpatient appointment, and sitting with a patient while the carer had a short break.

The fourth study <sup>124</sup>, undertaken in the Netherlands, was of a support programme provided by home helps. The programme consisted of practical and emotional support, intended to strengthen the main carer's sense of competence and feeling of being able to care for the dementia patient at home.

**Sample sizes:** The study sample in the evaluation of the augmented domiciliary service <sup>130; 269</sup> comprised 38 patient–carer pairs; the sample size in the other UK study <sup>283</sup> was unclear. The Netherlands' study <sup>124</sup> reported the findings of secondary analysis on the experimental group only (49 pairs). In the original study, however, 138 patient–carer pairs had been assigned to either the experimental or control group.

**Participants:** In all four studies, participants included carers of people with dementia. There were some instances of samples consisting of patient–carer dyads <sup>130; 269; 124</sup>.

**Research methods:** All the studies used quantitative methods, control groups and pre- and post-tests, with the exception of one <sup>283</sup> which employed a post-intervention survey only.

**Outcomes:** Studies examined carers' sense of competence, coping, perceptions of whether they could continue to care for their relative at home without the support of the service in question, and levels of satisfaction.

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**Evidence relating to effectiveness:** The evidence suggests that provision of domiciliary care can postpone or reduce permanent institutionalisation. Domiciliary care may therefore be a useful additional service alongside other interventions for carers, which may help with overall coping and perceived levels of burden.

**Economic aspects:** No economic study addressing domiciliary care services was identified.

**UK studies:** See above.

**Gaps in the research:** Research examining the extent to which support tailored to individual needs can be built into 'packages' of care, to enhance carers' ability to cope, would be valuable.

### ***4.8 Physical environment (N = 3)***

<b>Study identification code numbers</b>	178, 183, 187
<i>(see Table 13 in Appendix 4)</i>	
<b>Care recipient group</b>	AD and dementia (3), schizophrenia (0), other serious mental illness (0)
<b>Setting</b>	USA (3)
<b>Main measures of effectiveness</b>	Standard outcomes measures (2)

**Interventions:** Two of the articles<sup>183; 187</sup> shared the same co-authors, and related to interventions involving five 90-minute home visits by occupational therapists. The aim was to provide physical and social environmental modifications and education in order to help carers modify their living space to address specific aspects of daily care that were perceived as problematic – for example, bathing or dressing. Likewise, the third study<sup>178</sup> assessed the needs of carers and the person supported in the home, and identified target areas for interventions that were then implemented.

**Sample sizes:** There were 25 patient–carer pairs in one of the studies<sup>178</sup>, compared with 171 carers in another<sup>183</sup>. The total number of participants was not given in the third study<sup>187</sup>, which presented the findings in the form of one detailed case study.

**Participants:** All three studies in this group focused on primary carers of people with Alzheimer's disease or other dementia. One study<sup>178</sup> used carer–patient dyads.

**Research methods:** Two of the studies<sup>178; 183</sup> adopted quantitative methods; just one<sup>183</sup> used a control group. Measures were taken at baseline and at follow-up evaluations. Detailed information about study methods and outcomes for the third study<sup>187</sup> was not given (readers were referred elsewhere).

**Outcomes:** Studies focused on the effectiveness of interventions in the home environment, as well as carer well-being in terms of self-efficacy and upset in managing dementia behaviours. Patient outcomes relating to behavioural problems and levels of dependency were also examined.

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**Evidence relating to effectiveness:** There is only modest evidence regarding the effectiveness of interventions for carers based on improvements or changes to the physical environment. The provision of equipment in the home was moderately effective in terms of continuing use by carers <sup>178</sup> although the research did not address whether such provision reduced negative aspects of caring for carers. The Occupational Therapy programme <sup>187</sup> was successful in changing carer attitudes towards dealing with problems with patients, but again this study does not report on the long-term benefits of problem solving in terms of carer experience. The study <sup>183</sup> of occupational therapy interventions based on environmental change did not identify any significant improvement on outcome measures except for a modest impact on burden and evidence of fewer declines in instrumental activities of daily living among the experimental group. However, this study was of interest because it did consider the differential impact of the intervention on different carers, leading the authors to conclude that such interventions might be effective for female, African American and spouse carers, but that it would require adapting for use with male and non-spouse carers. These findings reflect the importance of identifying differences between carers in relation to the effectiveness of interventions.

Although there is limited evidence to support the effectiveness of interventions geared towards changes in the physical environment, this is a generally under-researched area.

**Economic aspects:** None of the three studies reported the economic implications of changes in physical environment upon carers.

**UK studies:** None of the studies reported had taken place in the UK.

**Gaps in the research:** The effectiveness of these interventions in terms of carer experience requires further investigation. Research should also pay attention to the different needs of subgroups of carers and patients with regard to these kinds of interventions and focus more specifically on the long-term effectiveness of services and how far they can be seen to reduce permanent institutionalisation and enhance carer coping ability.

### **4.9 Supporting carers through memory clinics (N = 2)**

<b>Study identification code numbers</b>	138, 190
<i>(see Table 14 in Appendix 4)</i>	
<b>Care recipient group</b>	AD and Dementia (2), schizophrenia (0), other serious mental illness (0)
<b>Setting</b>	UK (1), Australia (1)
<b>Main measures of effectiveness</b>	Standard outcomes measures (2)

**Interventions:** The UK study <sup>190</sup> looked at the effects on carer well-being and patient memory of an early intervention with people with dementia and their families in a memory clinic. The Australian study <sup>138</sup> similarly investigated the

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impact of a memory clinic on the psychosocial health status and burden of carers of people with cognitive impairment.

**Sample sizes:** The UK study <sup>190</sup> involved 30 patient–carer pairs. There were 50 patient–carer pairs in the Australian research <sup>138</sup>.

**Participants:** Both studies gathered data from carers supporting people with dementia. The Australian study's <sup>138</sup> sample comprised mainly older women. The UK research <sup>190</sup> also involved interventions with key workers.

**Research methods:** Both studies had control groups, and used a repeated measures design including follow-up at 12 months in one case <sup>138</sup>, and 18 months in the other <sup>190</sup>. The UK study <sup>190</sup> used different methods to collect information. As well as administering standard measures, qualitative data were obtained through case notes, a self-report questionnaire, and interviews with key workers and participant carers and families.

**Outcomes:** The researchers investigated outcomes in relation to carer well-being, depression, burden and psychosocial health-related quality of life (including social interaction, alertness behaviour, emotional behaviour, sleep and rest, and recreation and pastimes).

**Evidence relating to effectiveness:** The effectiveness of attendance at memory clinics for carers is of interest because it points the way to exploring more fully how interventions aimed at the patient might impact on carer well-being. In both cases, studies report improved carer well-being <sup>190</sup> and psychosocial health-related quality of life <sup>138</sup>. However, neither of the studies reported any improvement in carer burden or knowledge of dementia after the intervention. This might be expected if the carer perceives the memory clinic as an intervention for the patient and any benefits accruing to the carer are understood to be related to assistance and services for the person they care for.

**Economic aspects:** No economic study addressing the economic aspects of memory clinics was identified. However, one study <sup>196</sup> compared a ten-day intensive training programme for carers with a memory-training programme for carers. Details of this study are reported in Section 4.2 (under 'Training') above.

**UK studies:** See above.

**Gaps in the research:** Memory clinic research is more developed in relation to services for people with mental health problems. It would be of interest to consider other interventions aimed specifically at the patient to examine the outcomes for carers, and how these services can be developed in ways that maximise effectiveness for both carer and patient.



## **4.10 Multidimensional approaches to caring interventions (N = 15)**

<b>Study identification code numbers</b>	29, 41, 52, 119, 127, 169, 171, 176, 203, 208, 238, 239, 260, 267, 268
<i>(see Table 15 in Appendix 4)</i>	
<b>Care recipient group</b>	AD and dementia (11); schizophrenia (2); other serious mental illness (2)
<b>Setting</b>	USA (6), UK (4), Canada (4), Spain (1)
<b>Main measures of effectiveness</b>	Standard outcomes measures (12), programme evaluation/satisfaction surveys (1)

**Interventions:** Some four papers<sup>171; 208; 238; 239</sup> were written about one US service, Medicare Alzheimer's Disease Demonstration (MADD). This was a randomised three-year study that assessed the effect of providing expanded community-based services, case management and carer support services at two different levels of resource (one higher than the other). Carers were given access to education and training about Alzheimer's disease and related topics, through case managers and support groups. Case managers also assisted in determining an appropriate service package to meet clients' needs, co-ordinated formal assistance and monitored the quality of services provided by demonstration service providers. Another piece of research<sup>127</sup> undertaken in the USA evaluated a multi-site family support demonstration project in Massachusetts that provided support services such as respite, support groups, educational groups, patient companion programmes and outreach to the families of people with serious mental illness.

The Caregiver Support Program, located in Ontario, Canada, was the subject of two separate articles<sup>29; 203</sup>. This intervention consisted of carer-focused health care, education about dementia and care giving, assistance with problem solving, regularly scheduled in-home respite, and a self-help family carer support group.

The four UK studies<sup>41; 176; 260; 268</sup> are discussed in more detail below. Three provided early intervention, in two cases<sup>41; 268</sup> for people with Alzheimer's disease or other form of dementia, and in the third case<sup>176</sup> for young people between the ages of 16 and 25 experiencing psychosis.

**Sample sizes:** The study samples in three studies<sup>41; 52; 176</sup> numbered 37 or less. At the other extreme, the total demonstration sample in MADD<sup>171; 208; 238; 239</sup> included 8138 individuals, who received a baseline assessment. For technical reasons, some clients were excluded from the analyses in the various articles but even so numbers were still in the order of over 5000.

**Participants:** Study participants included carers, carer-patient pairs, families and relatives and, in one study<sup>176</sup>, professionals (including consultant psychiatrists and occupational therapists). Some interventions focused on primary carers. Samples often comprised female carers rather than male carers.

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Two interventions were for younger people with schizophrenia: in one case, 18–30-year-olds<sup>169</sup> and in the other 16–25-year-olds<sup>176</sup>.

**Research methods:** The majority of the studies used quantitative, repeated measures. Four<sup>41; 127; 169; 268</sup> used mixed methods, and just one<sup>176</sup> adopted a qualitative approach. Over half had a control group. Follow-ups varied, from 12 months to up to 36 months.

**Outcomes:** Studies examined outcomes relating to carer stress, burden, depression, quality of life and support networks. Institutionalisation rates were analysed, and programme evaluations undertaken.

**Evidence relating to effectiveness:** The development of multidimensional approaches to carer services should provide opportunities for the positive aspects of different interventions to be combined as well as producing additional benefits. The studies included here do not support this, however. Generally, the studies report positive outcomes along one dimension or another, but there is little evidence that providing multidimensional approaches produces any 'added value'. The most comprehensive evaluation, of the MADD project in the USA, found small improvements in burden and depression in some sites, but no change when all the cases were combined<sup>238</sup>. One UK study<sup>268</sup> found no evidence that the interventions provided were associated with improved outcomes for people with dementia or their carers. The reported findings are therefore inconclusive with regard to the effectiveness of multidimensional approaches to services for carers.

**Economic aspects:** Four of the studies<sup>203, 208, 260; 268</sup> of multidimensional approaches reported an economic analysis. All four studies addressed elderly patients with dementia, and one study<sup>260</sup> included elderly individuals with any type of psychiatric disorder.

All but one of the studies<sup>268</sup> included some type of break from caring in the package of care. Three studies<sup>208; 260; 203</sup> offered in-home respite. All studies except one<sup>260</sup> included some form of educational intervention, and support groups<sup>203; 208</sup> or changes to the physical environment<sup>208; 260</sup> were offered in two studies each.

Findings on cost-effectiveness were mixed. Two studies, which differed both in sample size and setting, found that the interventions were not cost-effective. The US study<sup>208</sup> reported that carers appeared to have substituted the intervention services for those already used. The other study<sup>268</sup>, based in the UK, reported higher use of residential and nursing home placements in the intervention group, which resulted in higher costs. The second UK study<sup>260</sup> found that low-frequency packages of care were cost-effective relative to usual care, while the Canadian trial<sup>203</sup> reported a cost-per-QALY that compared favourably with other health care interventions.

**UK studies:** One study<sup>176</sup> evaluated TIME, an occupational therapy initiative for young people experiencing psychosis. It offered a range of (unspecified) interventions on an individual, family or group basis. An individual programme of therapy was developed in collaboration with each client and, when appropriate, their family. Another study<sup>41</sup> evaluated SPECAL, a dementia care service.

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Service components included the 'Friday Group' with 24-hour care for clients and carers, the use of a day unit and the provision of carer support services, supported respite care, a range of home-based care, and preparation towards the transition into institutional care.

The third study <sup>268</sup> evaluated whether early, appropriate interventions would be associated with better outcomes. Study participants received either an intervention from a project dementia care specialist or usual primary care treatment. An option appraisal of services for elderly people with psychiatric disorders was reported in the last study <sup>260</sup>. This involved identifying and measuring both the costs and the benefits involved in alternative care packages for different condition groups. Consideration was also given to costs and benefits from the point of view of carers.

**Gaps in the research:** There is clearly a need for multidimensional service provision to be evaluated more thoroughly than has been the case so far. Multi-site, multi-perspective and multidisciplinary research is required to successfully evaluate the effectiveness of multidimensional services. In particular, attention should be given to the 'added value' provided by comprehensive service planning and delivery as well as the extent to which these services can succeed in developing a range of services that reflect and respond to the diversity of carer experience.

### **4.11 Miscellaneous (N = 8)**

<b>Study identification code numbers</b>	27, 28, 163, 166, 167, 177, 232, 250
<i>(see Table 16 in Appendix 4)</i>	
<b>Care recipient group</b>	AD and dementia (6), schizophrenia (0), other serious mental illness (2)
<b>Setting</b>	USA (3), Canada (2), UK (2), Italy (1)
<b>Main measures of effectiveness</b>	Standard outcomes measures (5), programme evaluation/satisfaction surveys (4)

**Interventions:** One of the US studies <sup>167</sup> was a qualitative case study of one carer's experience of the amount, type and impact of formal community support services. In the second study <sup>27</sup>, participants were randomly assigned to one of four interventions or a waiting list control group. The interventions included a cognitive stimulation programme for the carer-patient pair, dyadic counselling with each pair, dual supportive seminar groups for the carer and patient, and an early-stage day care programme that provided respite care and education/training for the carer and a social environment or activities for the person supported. The third study <sup>250</sup> comprised a two-year demonstration project <sup>250</sup> in Minnesota, USA, providing outreach services to the patient's home and offering crisis placement services in a specialised unit.

A study <sup>28</sup> from Canada evaluated a Network Therapy programme with spouse carers of people with dementia. A network therapist worked on a one-to-one basis with carers to establish goals aimed at increasing existing levels of informal and formal support. The other Canadian study <sup>166</sup> compared carers who

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used (prescribed) psychotropic drugs with carers who were non-users in order to identify differences in coping styles between the two groups.

One of the UK studies <sup>163</sup> assessed an initiative involving specially designed documentation intended for multidisciplinary, multi-agency use, and to be kept by the carer at home. The carer, and other professionals, contributed to the document, which could be shown to the GP, hospital or day care centre if necessary. In this way, the record served as a link between carer and professionals; at the same time, the carer was better informed regarding the care of the person supported. The second study <sup>232</sup>, discussed in more detail below, evaluated a UK-based assertive outreach programme, the Daily Living Programme (DLP).

The study from Italy <sup>177</sup> compared an established home hospitalisation service (HHS) for elderly patients with advanced dementia with patients in a general medical ward. The HHS enabled diagnostic and therapeutic interventions, usually performed in hospital, to be carried out at home. The researchers were interested in the impact on carer stress levels and the requirement for long-term institutional care.

**Sample sizes:** Two studies <sup>28; 167</sup> had very small samples, of seven or fewer. Some 103 carer–patient pairs took part in the study <sup>27</sup> comparing four different treatment programmes. Some 194 carers participated in the largest study <sup>166</sup>, which examined psychotropic drug use research <sup>166</sup>.

**Participants:** One study was specifically for spouse carers <sup>28</sup>. Women carers, rather than men, were the main study participants. There was one intervention for people with advanced dementia <sup>177</sup>, and another for people in the mild to moderate stages <sup>27</sup>. Community mental health members also took part in the evaluation study of carer-held records.

**Research methods:** Four studies <sup>27; 177; 232; 250</sup> were quantitative, two <sup>28; 163</sup> used a mixed-methods approach, and there was one <sup>167</sup> qualitative study. One study <sup>166</sup> undertook secondary analysis of an earlier piece of research. About half of the studies adopted a repeated measures approach.

**Outcomes:** Not surprisingly given the diversity of the studies in this category, outcomes were similarly varied. The more common ones included stress appraisal, psychological well-being and social support.

**Evidence relating to effectiveness:** Five of these interventions reported some degree of effectiveness ranging from a reduction in depressive symptoms through cognitive stimulation <sup>27</sup> to carer empowerment <sup>163; 167</sup>. It is the innovative approach that these interventions represent that is of most interest, particularly the work <sup>163</sup> on care plan documentation packs and Network Therapy <sup>28</sup>. Although the former <sup>163</sup> required some redesigning in the light of users' comments, carers generally felt the packs to be a positive step in their caring role. The outcomes from the Network Therapy approach <sup>28</sup> suggested that carers were drawing on additional assistance from extra carers and that they were using formal services more and more often.

**Economic aspects:** Two studies <sup>232; 250</sup> in this category addressed the cost-effectiveness of assertive outreach for patients. One study <sup>232</sup> evaluated a UK-

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based assertive outreach programme, the Daily Living Programme (DLP). The DLP was home-based care, consisting of 24-hour, 7-days-a-week access to care (including access to a walk-in emergency clinic) provided by a multidisciplinary team; carer support was part of the package. Patients with severe mental illness were randomly assigned to either DLP, or to DLP and then standard care, or to standard hospital care; follow-up was four years in duration. Little between-group difference in clinical outcomes was found, but both patients' and relatives' satisfaction levels were significantly higher in the DLP group. The DLP was found to be more cost-effective than hospital-based care in the short term (20 months), but the advantage disappeared over the second phase (30–45 months).

The second study <sup>250</sup> that addressed cost issues was the two-year demonstration project <sup>250</sup> in Minnesota, USA. The patients in this study were primarily those with mental retardation, but over 80 per cent suffered concurrent psychiatric illness. The control group was hypothetical and constructed using expert opinion on resource use by the intervention group in the absence of the demonstration project, combined with data on a small sample of patients unable to access the services over the study period. The study concluded that the intervention was cost-saving.

**UK studies:** Details of the only UK study <sup>232</sup> are reported in the 'Economic aspects' section above.

**Gaps in the research:** These studies reflect the importance of developing innovative approaches to working with carers and experimental projects that allow the effectiveness of these approaches to be developed and studied.

## Section 5 Economic aspects of interventions to support carers

This section reports on the 13 studies with an economic component that were included in the review. The study selection is outlined first, as a preliminary to documenting the main part of the analysis. For the sake of consistency, we use the same format and headings that were applied to each of the intervention categories in the Section 4.

### **5.1 Inclusion criteria for economic evaluations**

The search strategy outlined in the methods section yielded 130 hits. These were reviewed and 50 excluded as being not relevant to the study question, in line with the criteria outlined in Section 2 Methods section. Eighty references were retrieved. Multiple references to the same study (6), those without any costs (21), references that could not be retrieved within the time scale of the study (14) and studies in which no intervention was considered (4) were excluded. Literature reviews and burden of illness studies (16) were used to inform the methodology section, but were excluded from the list of studies. No systematic review or meta-analysis was found. One study included no measure of effectiveness (Kirchner *et al.*, 2000), three studies were uncontrolled (Cox and Reifler, 1994; Melzer, 1990; Reifler *et al.*, 1999) and two did not estimate the cost of the intervention (Roberts *et al.*, 1999; Weinberger *et al.*, 1993). The remaining 13 studies that could be classified as economic evaluations were reviewed and a overview table of findings is presented below. (For a more detailed summary table, see Appendix 5.)

### **5.2 Studies with an economic component (N = 13)**

<b>Study identification code numbers</b>	196, 200, 201, 203, 208, 232, 242, 250, 260, 261, 263, 268, 274
<b>(see Appendix 5)</b>	
<b>Condition group</b>	AD and dementia (5), schizophrenia (2), other serious mental illnesses (6)
<b>Setting</b>	UK (6), USA (4), Australia (1), Canada (1), Netherlands (1)
<b>Main measures of effectiveness</b>	Standard outcomes measures (7)

**Interventions:** Types of interventions included in the economic studies included three family intervention studies<sup>274; 261; 263</sup> and breaks from caring, comprising one study of day care services<sup>200</sup> and one of mixed respite services<sup>201</sup>. Educational strategies<sup>196</sup> and technological interventions<sup>242</sup> were addressed by one study each. Four studies were of multidimensional interventions and all focused on patients with dementia, although one<sup>260</sup> had a

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wider scope, examining elderly patients with any type of psychiatric disorder. A Canadian study <sup>203</sup> included a care-giver support programme, comprising one-to-one educational visits by a nurse, in-home respite and an invitation to join a support group. A study <sup>208</sup> set in the USA examined the impact of a case management and community care package, including education and training, support groups, day care services, home help, equipment supply, and counselling services. The two UK studies of multidimensional interventions were an option appraisal exercise that examined the impact of differing resource levels of packages of care <sup>260</sup> and a psychosocial intervention by a dementia specialist, including the provision of information and support <sup>268</sup>. Two studies were classified under the 'Miscellaneous' category. Both reported on assertive outreach programmes for persons with severe mental illness <sup>232</sup> or mental retardation <sup>250</sup>, but one of the studies <sup>232</sup> included support and education for carers.

Studies of single interventions for which no economic analysis could be found included studies addressing respite care (in-home or in an institution), educational strategies other than formal training, counselling, changes in physical environmental, and support or social groups. Although no study addressing memory clinics was found, a memory retraining programme served as a control group in one study <sup>196</sup>.

**Sample sizes:** Sample units employed in the studies fell into three categories. Three focused on client–carer pairs: these ranged in size from 50 to 102 pairs. Seven studies enrolled patients: the smallest contained 36 patients <sup>274</sup> and the largest study included an assessment of over 5000 patients <sup>208</sup>. Where the number of carers was specified, fewer carers than patients were assessed and it was unclear if all patients in the studies actually had a carer. Two studies enrolled carers, with sample sizes ranging from 60 <sup>203</sup> to 73 <sup>261</sup>. One study was an option appraisal exercise and enrolled no actual patients or carers <sup>260</sup>.

**Participants:** Study participants could be classified under two broad diagnostic categories. Firstly, there are studies of elderly patients with psychiatric disorders. This included Alzheimer's disease (two studies), dementia in general (two studies) or mental infirmity (EMI) (two studies). In the latter group, one study reported patients as suffering from senile or arteriosclerotic dementia (69 per cent), depression (9 per cent), and mania (3 per cent) or acute confusional state (3 per cent) <sup>201</sup>. Secondly, there were studies of severe mental illness. These included people with schizophrenia (2) and 'acute psychiatric illness' (1), comprising people with diagnoses of schizophrenia, depression and neurosis <sup>200</sup>. One study of patients with mental retardation reported that 82 per cent had diagnosed psychiatric co-morbidity, including schizophrenia, other psychotic disorders, personality disorders, mood disorders and impulse control disorders <sup>250</sup>. Two studies involved people with a range of diagnoses. One study <sup>232</sup> included people with schizophrenia, mania, neurosis and depression, and the other <sup>263</sup> had people with 'severe mental illness' and concurrent mild mental retardation.

Details of carer characteristics were less frequently reported, with just 6 of the 13 studies providing any details. No study of young carers was identified.

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Baseline carer characteristics were reported by three of the seven studies of elderly patients with psychiatric disorders and by just one of the six studies of patients with severe mental illness <sup>274</sup>. Mean carer age was reported only by the three studies of elderly patients and ranged from 65 <sup>268</sup> to 68 <sup>196; 203</sup>; five studies reported the proportion of spouse carers, two reported carer social class <sup>196; 274</sup> and three reported the proportion of female carers, which ranged from 54 per cent <sup>196</sup> to 72 per cent <sup>203</sup>.

**Research methods:** Of the 13 studies, seven were RCTs. There were two non-randomised controlled studies, one observational study and one case series study <sup>201</sup>. The two remaining studies were an option appraisal exercise <sup>260</sup> and a controlled before and after study <sup>196</sup>.

The duration of studies (including follow up) ranged from 6 months <sup>203; 263</sup> to 4 years <sup>232</sup>, 10 of the 13 studies were of at least one year in duration and six studies collected data for at least 2 years.

**Outcomes:** Seven of the 13 economic studies included carer- or family-specific measures. These included carer burden or stress (four studies), family burden or stress (two studies), carer health (five studies), carer satisfaction (three studies) and quality of life (one study). One study included a measure called 'service benefits' (incorporating notions of freedom or relaxation for the carer) <sup>201</sup> and another study included measures of loneliness and isolation, carer coping strategies and an assessment of social network <sup>268</sup>. One study that reported multiple measures presented self-reported measures of unmet carer need for support <sup>208</sup> and another measured carer perception of patient benefit <sup>260</sup>. Carer utilisation rate of support services was not reported as a measure of outcome by any of these studies.

Measures of effectiveness that involved no direct assessment of the carer were also found. The institutionalisation rate of patients was reported in five studies. One study of the effect of a family intervention, measured effectiveness by only the patient relapse rate <sup>261</sup>. Only one study included a measure of indirect benefits (patient earnings) <sup>274</sup>.

The impact of changes in process was also evaluated. Delaying the delivery of an intervention was reported by one study <sup>196</sup> and of switching patients from intervention to control care by another <sup>232</sup>. Differences in the care setting were explored by three studies <sup>200; 232; 263</sup> and differences related to the type of professional delivering support by another <sup>268</sup>. A family-focused intervention was compared with a patient-focused intervention by one study <sup>274</sup>.

**Evidence relating to effectiveness:** Six studies found no between-group differences in measures of effectiveness; five studies reported some positive findings, although two of these did not report whether these were statistically significant. In two studies, the effectiveness of the intervention was unclear: one study used estimates of benefits derived from expert opinion, rather than direct measures <sup>260</sup> and the other reported no measure of benefit for the control group <sup>250</sup>.

In terms of cost-effectiveness, five studies <sup>201, 232, 260, 263, 274</sup> reported the intervention to be cost-saving, five studies <sup>196; 200; 242; 250; 261</sup> found the



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intervention to be cost-effective in certain circumstances and two studies<sup>206;</sup><sup>268</sup> found the intervention was not cost-effective. The cost-utility analysis found the intervention compared favourably with other health care interventions in terms of its cost per QALY<sup>203</sup> (see Section 6.2.4). Further details of the findings are reported in the main section of the literature review, classified by type of intervention.

**Economic aspects:** Studies qualified as economic interventions if they included measures of costs (including the cost of the intervention), measures of effectiveness and a comparison group. Thirteen studies were identified using these criteria. Of these, only one study provided a summary index of cost-effectiveness and so could be termed a full economic evaluation<sup>203</sup>. However, where equivalence of between-group effectiveness had been demonstrated for primary outcome measures, there was no need to synthesise costs and effects. Five studies of this type – known as cost minimisation analyses – were found<sup>208; 232; 242; 263; 268</sup>. One study<sup>203</sup> also found equivalence of effectiveness, but an incremental cost per QALY was estimated from the change in quality of life from baseline in order to allow comparisons with alternative uses for resources to be made.

The direct costs estimated included health care costs (reported by all 13 studies), social services costs (10 studies) and criminal justice system costs (two studies). Carer utilisation rate of health services was reported by two studies<sup>196; 203</sup>. Out-of-pocket expenses were included by four studies and an attempt to estimate the direct cost of carer time was made by one study<sup>260</sup>. However, the resource use implications for this category of cost were explored by a further two studies<sup>201; 208</sup>. Indirect costs were measured by two studies; in one of these, changes in productivity were included on the benefit side of the analysis<sup>274</sup>.

Eight studies collected cost data prospectively; seven studies reported costs and quantities separately, allowing findings to be generalised to other settings and six of these undertook a statistical analysis of costs. It was unclear if any study was originally powered to detect statistical differences in cost-effectiveness.

**UK studies:** Six of the 13 economic evaluations were set in the UK. Half the studies were of elderly patients with psychiatric disorders or dementia, two addressed patients with severe mental illness and the remaining study was of people with schizophrenia.

### **Carers of elderly patients with dementia**

No RCT was identified among the UK studies for this carer-patient group. One study was an option appraisal exercise, based on evidence from the literature, expert opinion and accounting costs<sup>260</sup>. Another was a case series with matched controls that included a total of 50 carer-patient dyads<sup>268</sup> and the third study also used matched controls in a case series design – this study included over 100 patients, but only 53 carers<sup>201</sup>. This study examined the effect of a multifaceted respite service, whereas the other two studies examined a broader package of services. Findings on effectiveness were mixed (one positive, one neutral and one unclear);

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evidence for cost-effectiveness was also inconclusive and authors indicated the need for more targeted and better-designed research to determine the circumstances under which cost-effectiveness might be established.

### **Carers of patients with schizophrenia or other serious mental illness**

Two studies were RCTs<sup>232; 200</sup> and the third was an observational study with concurrent controls<sup>261</sup>. The study of a Daily Living Programme (fashioned on the Australian assertive outreach model) followed a group of 136 patients over a four-year period<sup>232</sup>. The number of carers included in the study was unclear and the only carer-related outcome measure reported was carer satisfaction; this was found to be significantly higher in the intervention group compared with the control group which received 'standard care'. The intervention was found to be cost-effective, both in the short term (20 months) and when the whole study period of 45 months was considered, although a decline in cost-effectiveness over time was observed: no evidence of cost-effectiveness was found in the final year of the study. The authors discussed this finding in the context of an attenuation of DLP care that occurred due to adverse media publicity and that resulted in the DLP team relinquishing control of inpatient admissions and discharges.

The other two studies were of shorter durations. A one-year study compared day hospital with routine inpatient care for patients with acute psychiatric illness<sup>200</sup>. Impact on carers was assessed using the General Health Questionnaire – for which no between-group difference was found – and using the Social Behaviour Assessment Schedule score as a proxy for carer burden. Using the latter measure, a statistically significant advantage for the intervention group carers was reported and the authors reported the intervention to be cost-saving. This conclusion was supported by the findings of a nine-month study comparing routine treatment with an array of family interventions, targeted at carers with high or low levels of 'expressed emotion' (EE)<sup>261</sup>.

A significant reduction in patients' relapse rate was found in the intervention groups, and the consequent reduction in health care costs offset the costs of the intervention.

**Gaps in the research:** No study focusing on either acute or chronic depression, eating disorders, anxiety disorders or substance abuse was identified. Neither were any studies of the economic implications for young carers of patients with any mental illness found. Another research gap included studies measuring key process outcomes, relating to the structure, delivery and organisation of services. Studies of single interventions for which no economic evaluation could be found included studies addressing respite care (in-home or in an institution), educational strategies other than formal training, counselling, changes in physical environmental, and support or social groups. Few studies appeared to be powered to detect statistically significant differences in effectiveness outcomes; for economic evaluations, where quality of life measures may be employed, even larger sample sizes may be required to

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detect statistically significant differences than is the case for measures of clinical effectiveness.

There is a need to identify which, and what combination of, elements in a multidimensional package are cost-effective and for whom. There is scope for further economic research in all patient groups and all interventions, with the possible exception of assertive outreach for patients with schizophrenia or other serious mental illness.

## **Section 6 Effectiveness and cost-effectiveness – issues for future research commissioning**

This section explores some of the key issues and questions that have emerged during the scoping study in relation to effectiveness and cost-effectiveness issues for services for carers of people with mental health problems. The preceding analysis found that most of the 204 evaluation studies were experimental or quasi-experimental investigations of single interventions for carers of people with Alzheimer's disease or other dementia. Just over one-quarter of studies included follow-up at three months or over; longer-term follow-up of two years and over was rare.

The majority of studies used quantitative methods, such as randomised and non-randomised controlled trials, and before-and-after (uncontrolled) studies. Most studies used standard outcome measures to evaluate effectiveness, rather than evaluated outcomes that had been informed from input by carers themselves. If appropriate 'off-the-shelf' measures were not available, researchers either devised a brand new measure using their own self-developed item scales or alternatively selected relevant items from different existing measures and pooled them into a new configuration. Carer burden, stress, coping, physical health, emotional well-being, depression and knowledge levels were commonly assessed. As far as cost-effectiveness was concerned, most studies included health care costs and social services costs. Just one study valued carer time; two assessed changes in carer earnings.

This section considers how these findings can inform future research commissioning. The first part explores the concept of effectiveness and how this has been applied to studies of interventions for carers of people with mental health problems. The second part goes on to consider the concept of cost-effectiveness. Both discussions raise themes that embrace the main methodological and implementation limitations encountered in the literature review. It is important that these are taken into account when commissioning future research.

### **6.1 The concept of effectiveness**

Defining effectiveness is complex and requires us to consider more than the outcomes of interventions. Of particular importance for this area may be the inclusion of measures of process in evaluation design. Other issues also need to be considered in designing and evaluating services, including time factors, needs-related factors, multiple perspectives, and methodological issues.

At a simple level, effectiveness can be defined as 'the extent to which a program meets its stated goals and objectives' (Schalock, 1995). Yet providing evidence for this can be complex:

***The evaluation question sounds simple enough in the abstract. But what looks elementary in theory turns out in practice to be a demanding enterprise. Programs***

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*are nowhere near as neat and accommodating as the evaluator expects. Nor are outside circumstances as passive and unimportant as [she] might like. Whole platoons of unexpected problems spring up.*

(Weiss, 1972, quoted in Smith and Cantley, 1985: 1)

Thus it might be argued that one of the reasons why existing evidence regarding the effectiveness of interventions to support carers of people with mental health problems is ambiguous is that no intervention is simple. Rather, interventions are complex: they involve various stakeholders including carers, patients and professionals; they may have multiple components, any of which can be effective, either alone or in combination; carers may have differing needs or different circumstances that affect the extent to which they are able to respond to particular interventions. There may be different kinds of interventions capable of achieving the same objective and therefore effectiveness might refer to a comparison of possible alternatives to identify the best (for example in relation to cost-effectiveness).

Effectiveness should therefore not be viewed simply in terms of the achievement of outcomes. If we are to understand how and why interventions are successful, we need to develop more comprehensive approaches that embrace diversity of carer experience, some understanding of how interventions work and why, and a more open approach to the measurement of outcomes.

### **6.1.1 Evaluation model: process, structure and outcome**

The Donabedian 'structure, process and outcome' model is a useful starting point for considering aspects of service delivery and evaluation that require further attention.

As far as 'structure' is concerned, this would involve measures of effectiveness that address a programme's framework and setting, such as the location for the intervention, service and staff (Wagner and Guild, 1989). In particular, issues of accessibility need to be considered in relation to carers' needs; for example, rural carers may not find it easy to access facilities provided in large towns or cities (see, for example, Herman *et al.*, 1996).

'Process' evaluations aim to give an understanding of how a service operates and how it produces what it does (Smith and Cantley, 1985; Ovretveit, 1998). It is argued that studying process can be useful for replicating services and finding out why something is effective (Walden and Baxter, 2001; Ovretveit, 1998), in other words, process evaluation can help to unpack the 'black box' (Patton, 1987) by showing how an intervention was delivered.

Where interventions are increasingly diverse, embracing education, support and other kinds of psychosocial interventions, it is worthwhile considering features of service implementation that can assist in identifying which components are effective. In addition to understanding more about which components are most effective, there is some agreement that knowing 'how much' of the intervention is required to achieve desired outcomes (Zarit and Leitsch, 2001; Bourgeois *et al.*, 1996) would also assist in developing services more effectively.

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The notion of process also embraces issues of service utilisation levels and the degree to which the intervention has been delivered according to programme objectives (Wagner and Guild, 1989). However, it is important to bear in mind that just knowing that a service such as a telephone help-line is available can provide carers with reassurance, regardless of the level of use. Clearly the relationship between service use and overall effectiveness needs to be reconsidered in the light of carer needs (see below).

It has also been argued that interventions need to be:

***... described, measured, and monitored to insure that caregivers are receiving [them] as prescribed and to permit replication of treatment effects with similar groups of caregivers.***

**(Bourgeois *et al.*, 1996: 80)**

This ongoing monitoring of the implementation of interventions has implications for evaluation research design where it is argued that measuring changes in outcomes for carers can occur without confirming that treatment goals, such as providing information or support, have actually been achieved (Zarit and Leitsch, 2001). Thus, ensuring that programme contents are adhered to can play an important role in establishing overall effectiveness as well as identifying factors that might affect outcomes. Consequently it is argued that implementation studies, while costly, can 'significantly enhance the replicability, generalizeability, and interpretation of future intervention research' (Bourgeois *et al.*, 1996).

In addition, it has been argued that the role of 'intervention agents' (facilitator, say, or therapist) should be given due attention in evaluation research design since the style of programme delivery could also be a factor that affects intervention outcomes (Bourgeois *et al.*, 1996).

How an intervention is implemented can consequently be seen as a factor in achieving effectiveness, and an issue that research designs need to address. It is also the case that ongoing monitoring of interventions can play an important role in ensuring that they are being delivered effectively.

Measuring outcomes is a common approach in evaluation studies of services for carers of people with mental health problems in order to examine the way in which a programme changes client attitude, behaviour or knowledge (see, for example, Wagner and Guild, 1989). Thus, measuring outcomes relies on being able to identify cause and effect (Wagner and Guild, 1989) and is most clearly demonstrated in studies that use control groups, pre- and post-test measures, experimental designs and standardised measures of outcome.

Standardised measures of outcome might focus on measuring changes in carer burden, health, stress or changes in rates of relapse etc. (Higginson, 1994). Their usefulness lies in their validity and reliability as standardised tests of behavioural or attitude change, yet there are also problems in assuming that such measures are always applicable to the unique experiences of all carers. Two main difficulties are identified in the literature, namely the problem of using generic versus specific measures and matching outcome measures to specific interventions.

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It has been argued that while generic measures have the advantage that they can allow for comparison across different types of care, they should also embrace specific issues pertaining to carers (Higginson, 1994) and consequently some have argued that more work is needed on measures that are relevant to carer experience (Gallagher, 1985). Others have argued that even specific measures, such as carer burden, may be inappropriate in some circumstances (Martin-Cook *et al.*, 2000).

So it is not just that we have to use measures that are appropriate to carer-related problems, they should also be appropriate to the intervention being evaluated. There is a view expressed that outcomes have tended to be conceptualised in global terms – such as a reduction in care-giver burden – with little consideration as to whether or not the specific intervention might produce these results (Bourgeois *et al.*, 1996; Knight *et al.*, 1993).

If the ultimate goal of effectiveness studies is to ‘assess the outcome or impact of services’ (St. Leger *et al.*, 1992) we need to understand how these outcomes can be measured and what factors might contribute to these outcomes beyond those included in the intervention.

While the ‘structure, process, outcome’ model is useful for providing us with a broad framework within which to locate some of the main issues facing both researchers and service developers, there are also some themes that appear to be particularly pertinent to the study of services for carers of people with mental health problems that we should also consider: the importance of time horizons for both study and design of interventions; the relevance of needs-based interventions; and the importance of multiple perspectives in study and design.

### **6.1.2 Time horizons**

The changing needs of care-givers over time is an aspect of caring that is well documented in work that has considered the ‘carer trajectory’, yet it is unclear how far interventions and/or evaluation research have been able to embrace this diversity in needs. The existence of multidimensional interventions, often managed by a key worker, suggests that the need for support to be tailored to carer and patient needs is recognised by some service providers.

For some, the care-giver ‘career’ is related closely to the illness experienced by the care receiver. Zarit and Leitsch (2001: 85) argue that Alzheimer’s disease, for example, brings particular issues because of its degenerative nature. The development of effective services for carers of people with mental health problems requires more consideration to be given to when an intervention is most appropriate both in terms of stage in carer career and illness progression. Similarly, in designing evaluations of these interventions, more care needs to be taken to explicate these issues in both research design and reporting of findings.

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### **6.1.3 Needs-based interventions**

One mechanism that might assist in ensuring that interventions are targeted at the 'right' carers at the 'right' time might involve a more needs-based approach to designing interventions and consequently experimental research designs. One of the difficulties in modelling this process may relate to the 'uniqueness' of each experience:

***... without a thorough knowledge and understanding of individual caregivers and their unique personal and psychological histories and circumstances, interventions can only continue to be designed for the 'average' caregiver, with average results.***

**(Bourgeois *et al.*, 1996: 79).**

This draws attention to the importance of considering individualised interventions for carers, or at least to developing generalised services that are flexible enough to deal with individual needs. Perhaps, too, it emphasises the importance of having a key worker assigned to the carer–patient dyad, who can act as a mediator between the dyad and service providers to match demand with supply.

With regard to evaluating interventions, consideration should be given to the diversity of carer characteristics and the potentially widespread needs expressed through these. Due attention can, and should, be given to major characteristics such as relationship to person supported, gender, age, socioeconomic status, and ethnic minority status as a minimum in identifying potential factors affecting the suitability and consequent effectiveness of interventions.

### **6.1.4 Multiple perspectives: involving carers and care recipients**

It is increasingly recognised that different stakeholder perspectives need to be included in both the design of an evaluation and in the design of interventions themselves (Walden and Baxter, 2001; Moriarty, 1999; Pollio *et al.*, 1998). Both 'pluralistic evaluations' (Smith and Cantley, 1985) and the 'fourth generation evaluation' (Guba and Lincoln, 1989) embrace this central principle. Recognising that an effective service should meet the needs or expectations of different stakeholders is a step forward in recognising that service users can play an important role in defining objectives as well as evaluating interventions.

It is possible for professionals to perceive an intervention as effective because they measure treatment effects and find these to have been achieved, while the care-giver does not necessarily view the treatment as effective. These differences stem from opposing views about what the treatment was designed to do (Bourgeois *et al.*, 1996). Increasingly, there is recognition that the aims of interventions should embrace care-givers' own expectations as well as those identified by professionals. However, these expectations need to be 'reasonable' (Zarit and Leitsch, 2001) and based on an acknowledgement that in some cases changes might be relatively minor.

It is not only carers and professionals who might be involved in this process of identifying effectiveness of services. Increasingly there is a view expressed



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that the perspective of the patient is also crucial (Zarit and Leitsch, 2001: S84).

Thus, greater consideration should be given to the ways in which the notion of effectiveness is understood by all the stakeholders involved in an intervention. Arguably, a needs-based intervention that is appropriately targeted at carers at a particular stage in their caring career and one that involves them and the patient in decisions about 'what' the intervention should be and 'how' it should be delivered stands a relatively greater chance of success in the longer term.

### **6.1.5 Summary comments: effectiveness**

This discussion has considered some of the main messages arising from the analysis of the studies included in the review. In particular, the complexity of identifying how 'effectiveness' might be understood by different stakeholders and the consequent difficulties of measuring this have been discussed. Furthermore, it has been suggested that a focus purely on outcomes in relation to effectiveness is inadequate to identify those elements of service delivery and implementation that contribute to the overall effectiveness of a service. Within these broad areas of concern, it has also been suggested that research, as well as interventions, should be more aware of carer diversity, both in terms of needs and stage of caring as well as diversity in illness and severity of illness.

A more realistic approach to evaluation methodology (see for example Pawson and Tilley, 1997) may help to overcome some of the weaknesses of outcome-focused research, although it is also true to say that intervention studies based on standardised measures and controlled experimental designs have strengths that should not be dismissed. This is an issue to which we return in the concluding discussion.

## **6.2 The concept of cost-effectiveness**

Cost-effectiveness is a measure of value for money that combines the costs and outcomes associated with an intervention (Drummond *et al.*, 1997). In many ways, the term 'cost-effectiveness' is self-explanatory. It involves the identification and measurement of inputs (costs) and outputs (outcomes) and their synthesis. Cost-effectiveness may be expressed as a ratio, such as the cost per unit of outcome. For example, we may estimate the costs of providing a counselling service for carers of patients with Alzheimer's disease and measure the effectiveness of that intervention in terms of the reduction of carer burden or improvement in carer's mental health. By linking the cost with the effectiveness, we have a summary index of cost-effectiveness, such as the cost of reducing carer burden by one point on a particular scale.

In terms of Donabedian's structure–process–outcome model, costs are incurred in the structure and process stages of an intervention; outcomes may be assessed at either the process or the outcome stage. To determine cost-effectiveness, however, the costs and outcomes associated with an alternative – or comparator – intervention must be made.

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### **6.2.1 Determining cost-effectiveness**

#### ***6.2.1.1 The role of the comparator***

To estimate the cost-effectiveness of an intervention does not allow us to say that an intervention is cost-effective. To determine whether or not an intervention is cost-effective, a *comparison* must be made between the costs and outcomes associated with one intervention, relative to another. The incremental cost of the intervention, relative to the comparator, can then be combined with the incremental effect to give an incremental cost-effectiveness ratio (ICER). The comparator intervention should be one appropriate to the study question and should reflect the intervention's 'opportunity cost' (see below). In the case of a new drug, the product would be compared with one or more drugs in current use in the relevant therapeutic area. In the case of an intervention to support carers of persons with mental health problems, the comparator would be usual care, with the intervention measured as an 'add-on' service. Alternatively, more than one intervention could be compared with usual care. Multiple interventions might be selected to enable the effects of different components in a package of care to be identified or to enable the effects of different process measures of the same type of intervention to be evaluated.

#### ***6.2.1.2 The treatment of costs***

Alternative patterns of care may change the way costs are distributed across patients and carers, health and social services and other agencies, such as charities. Consequently, it is appropriate to assume a societal perspective when analysing costs of interventions for carers of patients with mental health problems. Failure to do so may lead to unintended and undesirable cost-shifting, with adverse effects upon patient outcomes.

'Cost' is a measure of the resources used, the 'inputs' that are employed to achieve defined goals. Resources are, self-evidently, 'scarce' or limited and this means that there are alternative uses for resources. The value of the maximum benefit that could be achieved by diverting resources into an alternative, rather than the actual, use is the 'opportunity cost' of the actual use. Ideally, monetary values should reflect the opportunity cost, although this is not always the case. The cost 'perspective' chosen for the analysis will dictate whose costs are to be included. The widest perspective is 'societal', whereby costs incurred by any and all sectors and individuals as a result of introducing an intervention are estimated. These sectors may include the health service, the social services, the criminal justice system and the voluntary sector; individuals include both patients and carers. Some analyses may focus only on costs incurred by one or two of these sectors. If the perspective is that of the health service, for example, then only costs incurred directly in primary or secondary care may be estimated and although costs incurred by other individuals or sectors may be acknowledged, these will not be included in the costing analysis. Clearly, the viewpoint chosen for an economic evaluation may determine the results of the analysis. If carer time, for example, is not evaluated, then an intervention that maintains the carer in a principal role may

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look more cost-effective than one in which carer time is valued at market rate for formal carers ('replacement cost') (Drummond *et al.*, 1997). There are a number of advantages of conducting an analysis with a societal perspective. These include the facilities to disaggregate findings and present them from different perspectives and also to perform sensitivity analysis on costs pertaining to different sectors (such as exploring the impact of varying the cost assigned to informal care time). In addition, using a societal perspective at the outset may be less costly than adding on costs from other sectors retrospectively (Drummond and Jefferson, 1996).

### **6.2.2 Categories of cost**

Within the chosen perspective, costs may be categorised as 'direct', 'indirect' and 'intangible'. Direct costs are organising and operating costs borne within the relevant sector. Costs borne out of pocket by patients or carers and the value of resources they contribute to the caring process are also types of direct costs. Indirect costs are the value of loss of productivity (time off work or lost income due to the caring role). This is a definition used by economists and differs from the vernacular use of 'indirect cost' to mean 'overheads'. Intangible costs are those associated with pain and suffering and are also referred to as 'psychic' costs. These are rarely included in a cost analysis, but may be presented for consideration alongside the results of an analysis or may be incorporated into a measure of benefit such as quality of life.

Even if a societal perspective is adopted, is neither always desirable nor necessary to perform a comprehensive estimate of costs. If certain categories of cost are common to both the intervention and control, then these may be excluded from the analysis. In addition, if the aim of the analysis is to identify potential cost savings that may be redeployed, then the inclusion of overheads, or 'fixed costs' may lead to unduly optimistic estimates. For example, an intervention that reduces inpatient admissions may appear to save the high costs associated with use of a hospital bed. However, most of the costs that are included in the estimate – the equipment cost of the bed, and the apportioned capital and running costs – are fixed costs: they will be incurred regardless of whether or not the bed is occupied. In addition, some 'variable' costs may be 'semi-fixed' under certain circumstances: nursing, paramedical and medical costs incurred by the health service are unlikely to change in response to short-term fluctuations in bed occupancy. If no patient occupies the empty bed, these resources are unavailable for redeployment and cannot therefore be deemed to be savings. For this reason, economic theory favours the use of 'marginal' costs, whereby the additional cost of expanding a service by one unit is estimated. This overcomes the problems associated with the inclusion of fixed costs in average costing methodology, but data availability can be problematic. One category of costs that is worthy of particular consideration in the context addressed here is that of the cost of informal care.

### **6.2.3 The cost of informal care**

This cost may be particularly pertinent when considering the economic implications of support services for carers of people with mental health problems.

Informal care is clearly a valuable resource to society: if carers were unable or unwilling to take on this role, then replacement formal care would need to be found, funded by either the public or private sector or by both. The indirect costs of informal care for the mentally ill are likely to be long term rather than short term. Cultural and demographic trends may mean that the potential pool or supply of carers will diminish over time.

There are, however, considerable methodological difficulties associated with costing both lost productivity and informal care. Given the interplay of private (patient and carer), health and social service and other agency costs, it is inappropriate to take any other than a societal perspective when assessing the cost-effectiveness of alternative patterns of care.

Although the value of informal care is not assigned a monetary value by society, this does not mean it is of no value. From a societal perspective, its value may be recognised by considering the cost of its replacement. Should individuals be unwilling or unable to undertake the role of carer, society would have little choice but to fund formal care for patients in need. This would involve diverting resources away from other uses; the opportunity cost of those resources – the forgone benefit – determines the cost of informal care. If unemployment is high, then the opportunity cost may be lower than in a situation of 'full employment', when benefits to formal carers would have to be higher than those they currently receive in order to provide an incentive to change job. The value of the resources diverted is a measure of the cost of informal care and is known as 'replacement cost'.

From the perspective of the individual carer, the opportunity cost of caring may be understood in terms of the alternatives forgone as a result of taking on this role. Alternatives may include, firstly, employment opportunities; secondly, other unpaid work, such as caring for other family members; and thirdly, leisure activities, including holidays, social activities and relaxation.

With regard to employment opportunities, it is clear that these are not dichotomous in nature: it is not a question simply of the carer being employed or not, rather there are questions about the nature of the job, whether full- or part-time, pay levels, job flexibility and career opportunities. These will be determined both by the socio-demographic characteristics of the carer and the severity and nature of the patient's illness: for a young carer of a parent with schizophrenia or manic depression, the opportunity cost of caring in terms of lost employment opportunities could be immense. Economists call these 'indirect costs', but whether these should be valued is the subject of 'considerable debate and scepticism' (Koopmanschap *et al.*, 1995). The main objection to their inclusion is that economically active individuals' time will be valued more highly than the time of those who are economically inactive, and this may lead to an exacerbation of existing inequalities in the provision of care or support. On the other hand, the loss to society is real and may be better

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treated explicitly than ignored. There is disagreement also regarding the methodology used to value lost productivity. The traditional Human Capital Approach estimates the value of *potentially* lost income and some argue that the real productivity losses to society may be considerably less. In practice, firms may have internal labour reserves or flexible forms of labour supply may be available that will overcome short-term absences. In the case of carers, however, the problem is likely to be long term and may be impossible to determine. An alternative way of estimating indirect costs is the friction cost approach (Koopmanschap *et al.*, 1995). Lost productivity is measured by the amount of time firms need to restore the initial productivity level. This method would be useful for measuring the indirect costs for carers who have to reduce their hours, or change or give up jobs. It cannot assess costs associated with restrictions of job opportunity or career development.

Secondly, there are non-employment issues to consider and these will affect all carers. The alternative to informal care for the mentally ill patient may be other unpaid work, such as informal care of another type (such as minding grandchildren). In this case, the cost of the former may be taken either as the replacement cost for the latter, whether that is an indirect cost – lost productivity on the part of the parent – or a replacement cost, in terms of child-minding fees. In terms of leisure activities forgone, one possible approach found in the literature is to list the proportion of carers reporting certain types of opportunity cost, such as loss of enjoyment of retirement (Donaldson and Gregson, 1989). By then demonstrating that no statistically significant difference existed between intervention and control groups, the need to formally assign a monetary value to costs was thus obviated. Another approach is to measure the hours worked by carers in intervention and control groups (Fox *et al.*, 2000) and then to perform statistical analysis to assess the between-group differences. Simply valuing all carer time at replacement cost – differentiating between time spent physically caring (such as providing assistance with activities of daily living) and time spent supervising the patient – is an alternative approach (Spoor, 1988; Langa *et al.*, 2001). It should also be recognised that some time would be spent in the patient's company even if the patient were well.

Whatever the methods used to value carer time, double-counting must be avoided. If productivity losses are measured, working time forgone and thus measured must not also be valued at replacement cost (Souetre *et al.*, 1999). Equally, the opportunity costs of social activities forgone must not be assigned a monetary value if they are also encapsulated in a measure of quality of life.

### **6.2.4 The treatment of outcomes**

There are a number of forms of economic analysis, all differentiated by the method by which outcomes are estimated (Drummond *et al.*, 1997). A cost minimisation analysis (CMA) considers only costs; outcomes associated with alternative strategies are either assumed, or demonstrated, to be equivalent. Cost-effectiveness analysis (CEA) values outcomes in terms of a single measure of effectiveness. Measures of effectiveness may take the form of a single measure of clinical effectiveness – such as blood pressure or relapse

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rate – or be a multidimensional measure, such as a measure of ‘social support’ or ‘psychological well-being’ (Bowling, 1997). In cost–benefit analysis (CBA) a monetary value is assigned to outcomes, sometimes by asking patients (or others) about their willingness to pay for the benefit. This allows the relative intensity of preference to be indicated (Mullen and Spurgeon, 2000). Economic evaluations of this design are rare, although it is not uncommon to find a CEA inaccurately described as a cost–benefit analysis. Cost–utility analysis has ‘healthy years’ as its measure of benefit (Drummond and Jefferson, 1996). This involves assigning ‘utility’ to benefits and there are different techniques for eliciting values, including time trade-off, standard gamble and conjoint analysis (Mullen and Spurgeon, 2000). The value of the effects of an intervention may be rated on a scale from 0 (death) to 1 (perfect health) by a panel of patients, clinicians or lay persons, or indeed by an individual, using a validated scale such as the EQ-5D. This allows comparisons to be made between diverse clinical areas and technologies and is the approach currently favoured by the Department of Health as a policy-making tool. Life years gained may thus be modified to take into account the quality of those added years, a measure known as the QALY (quality-adjusted life year).

Since it is the relationship between the carer and patient – the caring process – that is the target of support, a family or dyad measure appears more attractive than one that is primarily carer- or patient-orientated. The difficulty with a measure that synthesises patient and carer(s) outcomes is that it is not possible to identify whether the benefit is attributable to both or is primarily experienced by one party at the expense of the other (Wenger *et al.*, 2000). However, this may be overcome by presenting a breakdown of components.

As well as considering whose outcomes should be measured, the issue of how outcomes are measured must also be addressed. It is unclear, for example, whether generic measures of health or quality of life adequately capture carer burden (Bell *et al.*, 2001). Some argue that unless generic measures are employed, comparisons with alternative uses for scarce resources are problematic and the case for diverting resources into carer support is thereby weakened (Zarit and Leitsch, 2001). Measures of quality of life are known to be associated with relatively large variance around the mean. For this reason, larger sample sizes may be required to detect statistically significant differences between the means than would be necessary if only clinical outcomes were assessed. If economic evaluations are to be conducted alongside clinical trials, then power calculations need to reflect the needs of the economic analysis as well as those of the clinical analysis.

### **6.2.5 Other issues**

#### ***6.2.5.1 Time horizons***

The time horizon for an economic analysis should be determined by a number of considerations. Firstly, there is the nature of the intervention. Short-term interventions, such as a brief counselling programme, will require shorter follow-up duration than will ongoing educational support. Secondly, patient prognosis (and the consequent expected duration of caring) needs to be

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considered. Carers of patients with severe dementia at risk of institutionalisation will need to be observed for shorter periods than will carers of newly diagnosed patients; refractory patients suffering acute psychiatric episodes will require long-term follow-up, whereas patients with acute postnatal depression may not. Thirdly, there are practical considerations, including the need to minimise sample attrition and the need to ensure that any changes in resource use (such as delayed institutionalisation) are measured. Costs incurred in the future should be discounted to present values.

### ***6.2.5.2 Modelling***

Constructing a model may be useful to explore long-term costs and outcomes. Uncertainty surrounding key variables can be investigated in a number of ways. Where variables are of known value now, but may change in the future, such as disease prevalence and carer supply, sensitivity analysis should be used. In the case of probabilistic variables (where there is a probability distribution associated with a variable) such as measures of effectiveness, other techniques such as Monte Carlo simulations may be used.

### ***6.2.5.3 Primary research***

However, the usefulness of a model depends largely on the quality of data it contains; there may be limited returns in investing resources to find data to populate models when the fundamental need is for better primary research. A general criticism of existing research is the lack of adequately powered and well-designed studies with suitable economic endpoints to inform policy-makers about the long-term consequences of alternative service configurations.

## **6.2.6 Summary comments: cost-effectiveness**

In summary, then, cost-effectiveness is a measure of value for money that combines the costs and outcomes associated with an intervention. It is a term that is meaningless in isolation: an intervention can only be cost-effective relative to some alternative or 'comparator'. For this reason, economic evaluations must measure not only costs and effects, but must do so for at least two alternative interventions, allowing incremental cost-effectiveness to be determined. The adoption of a societal perspective for the economic evaluation – in which all costs incurred by all stakeholder are considered – is recommended, because it allows the impact of the intervention on these different stakeholders to be understood. The treatment of the costs of informal care may be the most important factor in determining cost-effectiveness of support services for carers of persons with mental illness; however, the methodology is complex and problematic. The time horizon adopted in empirical studies is also highly pertinent in determining cost-effectiveness. Finally, expected changes in social demographic and morbidity trends may be explored using modelling techniques, provided that data of adequate quality are available: well-designed primary research is of paramount importance.

### **6.3 Conclusion**

Effectiveness and cost-effectiveness both consider outcome measures – they assess benefits. However, an intervention that is effective is not necessarily also cost-effective: this will depend on the *additional* value for money the intervention gives or does not give, compared with an alternative intervention. This discussion of conceptual and methodological issues pertaining to the idea of effectiveness and cost-effectiveness has generated a number of issues and recommendations regarding commissioning of future research in the area. These are listed below.

- Evaluations of effectiveness need to embrace ‘process’ factors in order to assist in the identification of how and why particular interventions work.
- Evaluations of effectiveness and cost-effectiveness need to use measures of outcomes that are both appropriate to the aims of the intervention and to carers’ needs. The issue of *whose* values are used in outcome measures and *how* those different values are added up, or summarised, is critically important.
- Evaluations of effectiveness and cost-effectiveness need to ensure that the diversity of carer experience and the nature of the illness with which the carer deals are adequately considered. This may require subgroups of carers and patients to be considered separately.
- Evaluations of effectiveness and cost-effectiveness need to embrace multiple or societal perspectives in order to capture the complexity of the caring experience.
- Evaluations of effectiveness and cost-effectiveness need to place the carer and patient dyad at the centre of a needs-based research design that acknowledges the contribution these stakeholders can play in designing effective service interventions.

A key implication of this kind of approach to designing studies of effectiveness is the need for multiple methods to examine different aspects of structure, process and outcome of interventions for carers (Smith and Cantley, 1985: 12).

Thus, qualitative and survey data can provide important contextual material alongside the quantitative methods most often applied in this field. Indeed, there is increasing recognition that the randomised controlled trial, while operating as a gold standard in clinical trials, is limited in terms of accommodating the issues identified above, and that there is a need for health services research to draw on a wider range of methods (Marks and Godfrey, 2000; Gowman and Coote, 2000). Increasingly commissioners of research in this field will need to consider how the kinds of issues identified in the literature review can best be addressed. This discussion of the issues relating to effectiveness and cost-effectiveness suggests that it will be increasingly necessary to draw on multiple methods for different aspects of research questions, which in turn will require a more complex and contextual approach to studying carer interventions.



## Section 7 Discussion of the review results

The preceding analysis has highlighted key issues regarding support for carers for people with mental health problems. These will be discussed under the following headings:

- Mapping the results
- Methodological issues and ideas for improvement
- Evidence on effectiveness of interventions
- Key messages and recommendations.

### **7.1 Mapping the results**

In terms of condition groups, most of the national and international research included in the review looked at Alzheimer's disease or other types of dementia (see Section 3, Figure 3.2). This emphasis no doubt reflects governments' growing concerns about predictions regarding the percentages of populations likely to suffer dementia, and the consequent economic implications. Studies undertaken specifically in the UK followed a similar pattern (see Section 3, Table 3.3). The majority of research looked at Alzheimer's disease, followed by schizophrenia and thirdly other serious mental illness. It is known that in the UK the most common mental health problems are depression, anxiety and eating disorders (DoH, 1999a), yet the review identified no studies focusing on these specific conditions (or substance abuse).

As far as the different types of interventions and services for carers for people with mental health problems were concerned, by far the majority of research was targeted at educational interventions (see Section 3, Table 3.2). Respite care and family interventions comprised the two next largest areas for study. The pattern differed somewhat in the UK, where most inquiries focused on family interventions (30 per cent). This emphasis is consistent with the NSF for Mental Health (DoH, 1999a) which indicates that family interventions for people with schizophrenia and other mental illnesses can be useful and/or effective in preventing relapses. It is perhaps with this in mind that the Department of Health has recently commissioned the organisation Making Space to produce a specification for a mental health carers' support service. This work was carried out at the same time as our scoping study, and the research teams delivered their report in 2002. Three research studies<sup>40; 92; 289</sup> involving family support workers from Making Space were included in the review.

One-quarter of the UK studies evaluated one form or another of educational intervention – which again is consistent with the emphasis placed upon education and training programmes, and information giving, in the two NSFs (DoH, 1999a; DoH 2001) and the national strategy for carers (DoH, 1999b). The provision of comprehensive, multidisciplinary services also features in current policy (DoH, 1999a), and the review did include four studies from this country that involved multidimensional approaches to caring interventions.

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However, only one economic evaluation of an educational intervention was identified.

What is a cause for concern, however, is the relative paucity of research evaluating the interventions and services that are flagged up in recent policy documents as potentially useful in supporting carers of people with mental illness (or carers *per se*). Respite care is an obvious example. As stated in Section 1, the government has made ring-fenced monies available to local authorities over a three-year period in the form of the Carers Special Grant to help them provide a wider range of breaks for carers. Less than one-fifth of the UK research studies included in the review looked at respite services, and only one economic evaluation addressing this issue was found. Other examples highlighted in recent policy as beneficial for (some) carers are support groups and counselling. Again, the proportion of studies looking at these types of intervention was minimal (2 per cent for each category group) and no economic analysis was identified. Telephone help-lines, electronic technology and home-based technology are all services cited as potentially valuable. We found no UK studies focusing specifically on interventions of these types at all. Likewise, recent legislation and the NSF for Mental Health (DoH, 1999a) all focus on carer assessment and care plans. Again, this was a neglected area as far as studies included in the review were concerned.

It is well documented that carers comprise a heterogeneous group, and that different groups of carers may benefit from different types of support. There is evidence that carers from ethnic minorities have some additional needs (DoH, 1999b), but at the same time it is known that these are not being met (SSI, 1998). Given that black and minority ethnic groups face a high risk of mental illness (DoH, 1999a), it is of concern that there were no UK intervention studies focusing on this particular subgroup of carers. Indeed, this group was invisible in the majority of the studies included in the review. Similarly, children and young people who take on caring responsibilities are singled out in UK legislation and policy documents. Once again, we found no studies looking at the effectiveness or cost-effectiveness of interventions and services for this specific group of carers.

### ***7.2 Methodological issues and ideas for improvement***

The mapping exercise showed that the majority of studies (80 per cent) included in the review were randomised or non-randomised controlled trials, before-and-after studies (uncontrolled) or post-intervention data. The remaining 20 per cent of studies used mixed methods, or qualitative methods (see Section 3, Table 3.4). Most studies were experimental or quasi-experimental. Longer-term follow-up over two years was rare. Seventy per cent of the research reports addressed effectiveness using standard outcome measures, usually as part of a battery of instruments. Commonly used measures included the General Health Questionnaire, the Burden Interview, the Center for Epidemiological Studies Depression Scale and the Positive and Negative Affect Schedule. (For a comprehensive review of quality of life

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measurement scales, see Bowling (1997).) If researchers felt that existing scales were not appropriate measures for their particular study, then they developed item scales specifically to suit their own purposes. Alternatively, they took subsets of different existing measures and combined them into a pool of items.

Generally speaking, the measures used tended to focus on carer burden, stress, coping, physical health, emotional well-being and depression – in other words, the negative aspects of caring. However, more recent research into carers' issues (Nolan *et al.*, 1996), has shown that carers can derive satisfaction from their care-giving activities. Standard measures of satisfaction have been developed (see, for instance, the Carers Assessment of Satisfaction Index (CASI) (Nolan *et al.*, 1998)) yet very few studies looked at caring from this point of view.

Alternative, and/or additional, ways to assess the effectiveness of interventions included programme evaluation surveys, satisfaction surveys, service utilisation rates, relapse rates, admissions to institutional care or hospital, and practitioners' observations of outcomes. Most of the studies with an economic component included health care costs and social services costs. One study valued carer time; two assessed changes in carer earnings.

Questions have been raised about the dominance and appropriateness of both quantitative methodologies and outcome measures. Bowling (1997) points out, for example, that the conceptualisation and measurement of health outcomes are controversial. Most existing indicators reflect a 'disease' model where pathological abnormalities are indicated by signs and symptoms. This fails to capture subjective indicators of health, such as pain and discomfort. The gap between satisfaction as reported by carers (in relation to, say, support groups) and lack of positive evidence from standard outcome measures suggests that these measures may require some reworking to reflect multiple perspectives of effectiveness. It is also worth exploring whether measures of burden, say, or psychological health are the best way to assess the effectiveness of an intervention.

The pre-eminence of quantitative methods is at the expense of more qualitative work that has the potential to shed light on why and how a particular intervention is perceived as effective, for whom, and in what circumstances (Pawson and Tilley, 1997). Recently, there have been calls (Marks and Godfrey, 2000; Gowman and Coote, 2000) to expand the evidence base in health services research from the traditional randomised controlled trials to encompass different methods. Qualitative research that is used together with a randomised trial, say, can help shed light on quantitative results (Fulop *et al.*, 2001).

The analysis of effectiveness, cost-effectiveness and gaps in research relating to the 11 intervention groups highlighted recurrent methodological weaknesses in the studies included in the review – for example: small sample sizes; problems with attrition; problems relating to the use of control groups; studies not having long enough follow-up to know whether the intervention in question was effective long term as well as short term, or alternatively to know whether

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carers needed time to further develop newly acquired skills. These limitations were frequently acknowledged by the authors themselves.

Studies that involve randomisation of patients between comparison groups may be inappropriate or misleading for evaluating the impact of interventions on their carers. Non-participation can be a particular problem in randomised designs: it is greatly complicated where patient consent has been sought but carers have not necessarily agreed to take part in the study. Although patient–carer dyads will be randomised (resulting in both randomly allocated patients and randomly allocated carers), some of the carers may then decline to participate and the sample of carers available for analysis will be self-selected and not random. In addition, some study patients may not have a carer, which would further reduce the size of the carer sample. As a result, the study may be under-powered for evaluating the outcomes and effects of interventions for carers, and the validity of the findings and their generalisability will be undermined. The comparison groups of carers may also differ in ways other than their experience of the intervention being considered. In this case, subgroup analysis will be required with further implications for sample size calculations. There may be circumstances where there are genuine reasons for not randomising, in which case adjustment for baseline differences assumes considerable importance. Clearly, the statistical design of studies for evaluating impacts on carers raises complex methodological and practical issues. Research teams commissioned to undertake evaluation studies need to be multidisciplinary (embracing both quantitative and qualitative expertise), and should include researchers with a track record of experience in the methodology of study design and outcome evaluation.

Problems relating to attrition are likely to be minimised if the type of intervention being studied is well defined and addresses the assessed needs of carers taking part in the study. Attrition rates may also be reduced if the intervention improves the care of the patient in some way, as it is known that one of the outcomes that carers want is services that provide quality care for the person they support (Nicholas, 2001).

There could well be a case for involving carers in the development of new interventions, and indeed this was done in a handful of studies included in the review. These tended to be in the area of educational programmes, where carers were consulted regarding the content. In principle, there is no reason why carers could not be involved in the decision making about any subsequent evaluation: the form of the evaluation, and the outcomes to be investigated to help decide whether or not it ‘worked’. There might then be more of a sense of ‘ownership’, which again should help reduce problems of attrition.

Research also needs to consider the duration and timing of an intervention alongside how it is implemented. Interventions need to be of sufficient duration and frequency so as to be meaningful, for example the occasional one-week short break for someone who has been heavily involved in caring for many years might be inadequate. The timing of interventions also needs to be thought through to ensure that they are provided at a time when carers need them and when carers are likely to be most responsive to them. It may be the

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case that interventions provided at inappropriate times have less long-term impact than those that are provided when carers do need them.

### ***7.3 Evidence on effectiveness of interventions***

Existing systematic reviews of interventions for carers of people with mental health problems have tended to be cautious in suggesting that evidence supports any particular interventions. Thompson and Spilsbury's (2001) systematic review of support for carers of people with Alzheimer's-type dementia found no conclusive evidence to 'support investment in support programmes or withdrawal of the same' (p.3). Similarly, the systematic review by Pusey and Richards (2001) of psychosocial interventions for carers of people with dementia concluded that there was no strong evidence supporting the effectiveness or otherwise of technology-based interventions, group-based interventions, individual-based interventions, or particular service configurations.

The preceding analysis has likewise identified a lack of clear evidence to support any specific interventions, although it is obvious that almost all studies have been able to identify some positive outcomes of services provided. While the methodological rigour required for a full systematic review was not employed in the present scoping study, any future research commissioning needs to bear in mind the point just made that many pieces of research suffer from methodological weaknesses. This reduces the likelihood of further systematic reviews being able to offer any more conclusive evidence.

Fundamentally, it is difficult to conduct research that embraces the complex configuration of carer and care recipient needs, expectations and experience, under conditions required for controlled experimental research designs. Alongside the difficulties associated with carers and care recipients, the complexity surrounding service delivery mechanisms also needs to be considered. To this end, it might be fruitful to investigate the value of an intervention from more of a contextual point of view. This might mean examining, for example, the structure of the service: how it is organised (single or multi-agency); how financially sound it is (short-term or long-term funding); how sustainable it is. Alternatively, it could mean investigating more of the process, nature and quality of service delivery. For instance, it is known (Nicholas, 2001) that carers want services that are accessible, responsive and individually tailored to their needs; and indeed, these characteristics have been identified as hallmarks of good services in policy documents (DoH, 1999b; DoH 2001).

### ***7.4 Key messages and recommendations***

The overall aim of the scoping study is to advise the SDO Programme as to what further research and development work should be funded in the areas of services for carers of people with mental health problems. The list below sets out key messages and recommendations that have recurred throughout the

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literature review, in particular in the 'Gaps in the research' sections at the end of each intervention category in Section 4.

### **Areas and questions for research**

- Evaluation studies need to be undertaken in key policy areas intended to give practical support to carers of people with mental health problems, in particular: carer assessment; care plans; breaks from caring; family support; the use of telephone help-lines and computer-based interventions.
- Comprehensive packages of care are prioritised, which means it would be valuable to examine carers' service provision in its entirety rather than separated out into discrete components, such as a time-limited training programme or the occasional short break.
- Research is needed to determine which, and what combination of, elements in a multidimensional package are effective and cost-effective, and for whom.
- There is a need to know more about the effectiveness of interventions in relation to different subgroups of carers, including: young carers; black and ethnic minority carers; spouse carers; male carers and female carers; working and non-working carers; carers of different patient groups.
- More research needs undertaking into the relationship between the different stages of an illness and specific interventions. For example, Goldstein's (1996) review indicated that psychoeducational programmes focusing on the family unit might be effective for first- or recent-onset schizophrenic patients, while those focusing just on relatives suggested greater effectiveness during later stages of treatment; hypotheses such as this require further investigation.
- Interventions should be implemented with a broader range of patient groups to examine their effectiveness for carers when transferred from one condition group to another. For instance, the majority of studies of respite targeted carers of people with Alzheimer's disease or other dementia; so, too, did all the training programmes. Family interventions, in contrast, focused on carers of people with schizophrenia and other mental illnesses.
- There is scope for further economic research in all care recipient groups and all interventions, with the possible exception of assertive outreach for patients with severe mental illness.

### **Research design**

- The quality of methodological rigour of studies should be improved.
- A wider range of research methods should be employed with a view to increasing the depth and breadth of data collected, and range of study participants.
- The value of, and emphasis on, standard outcome measures as the primary method of determining the effectiveness of an intervention should

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be reassessed, especially as the sensitivity of some carer burden measures is unclear.

- Studies powered to detect statistically significant differences in both effectiveness and cost-effectiveness measures would be valuable.
- More longitudinal studies are required to examine effectiveness and cost-effectiveness in the short and longer term.
- Innovative approaches to developing, implementing and assessing interventions for carers should be encouraged, drawing on carers' own expertise (Nolan *et al.*, 1996) in relation to the nature of the support required, how it is delivered and the way it is evaluated.

We are concluding this report with a quote taken from a literature review summarising articles from 1980 to 1990 on psychosocial interventions and respite care for carers:

***The appropriate question now is not whether interventions work but rather what interventions work best with what levels of strength with which kinds of caregivers caring for relatives with specific kinds of impairments.***

**(Knight *et al.*, 1993: 247)**

It seems to us that this judgement is as pertinent today as it was when it was first made in 1993.

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## **Appendix 1**

### **Distribution of references by electronic bibliographic source**

<b>Database</b>	<b>Host</b>	<b>Dates covered</b>	<b>Date searched</b>	<b>Hits</b>	<b>Filename</b>
AMED	Silverplatter/ARC	1985 – 2001/07	28/11/01	512	Amedcare.txt
ASSI	York Datanet		10/12/01	0	
BNI	Silverplatter/ARC	1994 – 2001/07	28/11/01	317	BNIcare.txt
Caredata	Internet	All	28/11/01	41	
CCTR	cd-rom	2001: issue 4	29/11/01	337	
CDSR	cd-rom	2001: issue 4	29/11/01	1	
Cinahl	Silverplatter/ARC	1982 – 2001/10	28/11/01	839	Cinmed.txt
DARE	Internet	Current	29/11/01	2	
Embase	Silverplatter/ARC	1984 – 2001/10	28/11/01	1589	Embcare.txt
HMIC – King's Fund Database	Silverplatter/ARC	1979 - current	28/11/01	506	Kingcare.txt
HELMIS					
Dhdata					
HTA	Internet	29/11/01	29/11/01	0	
Medline	Silverplatter/ARC	1981 – 2001/10	28/11/01	1565	Medcare.txt
NHS EED	Internet	29/11/01	29/11/01	25	
SIGLE	CD-ROM		10/12/01	64	
SSCI	Web of Science	1985-2001	10/12/01	268	savedrecs
Sociological Abstracts	Silverplatter/ARC	1986 – 2001/09	28/11/01	247	Socabcare.txt

Endnote library: 3755 after deduplication

An economics filter was applied to all the databases and records within the Endnote library were subsequently tagged as economics papers.

## **Appendix 2**

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### Search strategy for literature review

Su Golder, Information Officer CRD\*

The following search strategy was used on the Medline database and then converted for each subsequent database.

- 1 "Caregivers"/ all subheadings
- 2 caregiv\* in ti ab
- 3 care-giv\* in ti ab
- 4 carer\* in ti ab
- 5 informal care in ti ab
- 6 befriending in ti ab
- 7 home care in ti
- 8 home based care in ti ab
- 9 caretaker\* in ti ab
- 10 care taker\* in ti ab
- 11 ((family or families or neighbour\* or relatives) near2 (care or caring)) in ti ab
- 12 ((family or families or neighbour\* or relatives) near2 (support)) in ti
- 13 # 1 or # 2 or # 3 or # 4 or # 5 or # 6 or # 7 or # 8 or # 9 or # 10 or # 11 or # 12
- 14 explode "Mental- Disorders"/ all subheadings
- 15 "Mental- Health"/ all subheadings
- 16 mental disorder\* in ti ab
- 17 mental health problem\* in ti ab
- 18 mental illness in ti ab
- 19 psychiatric disorder\* in ti ab
- 20 mentally ill in ti ab
- 21 dementia in ti ab
- 22 schizophrenia in ti ab
- 23 alzheimers in ti ab
- 24 psychiatric problem\* in ti ab
- 25 mental health disorder\* in ti ab
- 26 mental disease\* in ti ab
- 27 psychiatric illness\* in ti ab
- 28 mental impairment in ti ab

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- 29 eating disorder\* in ti ab
- 30 cognitive disorder\* in ti ab
- 31 mood disorder\* in ti ab
- 32 anxiety disorder\* in ti ab
- 33 personality disorder\* in ti ab
- 34 anorexia in ti ab
- 35 bulimia in ti ab
- 36 explode "Substance-Related-Disorders"/ all subheadings
- 37 hysteria in ti ab
- 38 neuroses in ti ab
- 39 psychoses in ti ab
- 40 manic depression in ti ab
- 41 # 14 or # 15 or # 16 or # 17 or # 18 or # 19 or # 20 or # 21 or # 22 or # 23 or  
# 24 or # 25 or # 26 or # 27 or # 28 or # 29 or # 30 or # 31 or # 32 or # 33 or  
# 34 or # 35 or # 36 or # 37 or # 38 or # 39 or # 40
- 42 # 13 and # 41
- 43 (service\* or programme\* or program or programs or project\* or scheme\*)  
in ti ab
- 44 (support near2 care\*) in ti ab
- 45 (initiative\* or incentive\* or intervention\*) in ti ab
- 46 # 43 or # 44 or # 45
- 47 # 42 and # 46
- 48 # 47 and (PY >= "1985")
- 49 # 48 and (LA = "ENGLISH")

## **Appendix 3**

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## ***Appendix 4***

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Summary table of studies included in the  
review

## Services to Support Carers of People with Mental Health Problems

**Table 1 Day care services (N = 12)**

Study number	Author(s)	Sample	Care recipient group	Research methods	Intervention	Duration of intervention	Outcomes	Setting
34	Jarrott <i>et al.</i> (1999)	Carers (261)	Dementia	Quantitative. No control group. Pre-test. Follow-up (3 and 12 months)	Adult Day Service Programme	Not given	Standard outcome measures: benefits and drawbacks of programme; satisfaction	USA
35	Wells <i>et al.</i> (1990)	Carers (219): study group (155); wait list/control (64)	Dementia	Quantitative. Control group. Pre-/post-tests	Special Dementia Day Care Programme	Varied	Standard outcome measures: problem checklist; psychological problems; anxiety; depression; quality of life; guilt; grief	Australia
37	Dziegielewski and Ricks (2000)	Carers (26)	Dementia	Quantitative. Postal survey	Adult Day Programme (social model)	Varied	Programme evaluation and satisfaction survey	USA
78	Zarit <i>et al.</i> (1998)	Carers (324). Short-term (3 months) study group = 121; control group = 203. Long-term study group (12 months) = 73; control group = 120	Dementia	Quantitative. Control group. Pre-/post-tests. Follow up (12 months)	Adult Day Care	Minimum 2 days/week	Standard outcome measures: stress appraisals and well-being	USA

## Services to Support Carers of People with Mental Health Problems

**Table 1 Day care services (continued)**

Study number	Author(s)	Sample	Care recipient group	Research methods	Intervention	Duration of intervention	Outcomes	Setting
118	Chu (1991)	Patients (9); carers (9)	Dementia	Not clear	Day Care Centre	Not clear	Impact of day care programme on patient and carer	Hong Kong
121	Beisecker <i>et al.</i> (1996)	Carers (104). Study group = 52. Control group (non-users) = 52.	Alzheimer's disease	Mixed. Control group. Post-test	Adult Day Care	Varied	Semi-structured interview schedule: benefits and barriers to use of programmes	US
156	Johnson and Maguire (1989)	Carers (46)	Alzheimer's disease and related dementia; schizophrenia; depression	Quantitative. No control. Pre-/post-tests. Follow-up (4 months)	Day Away Centre	From 8 to 24 hours per week	Standard outcome measures: stress; patient behaviour	Australia
181	Adam <i>et al.</i> (2000)	Patient (1)	Alzheimer's disease (mild to moderate)	Mixed case study. Initial evaluation; follow-up (3 months)	Day Care Centre	13 weeks	Standard outcome measures: carer burden	Belgium
199	Cox and Reifler (1994)	Not stated	Dementia	Quantitative. No control. Pre-tests.	Dementia Care and Respite Services Programme (national demonstration project)	Varied	Standard outcome measures: multiple including problem behaviours	USA

## Services to Support Carers of People with Mental Health Problems

**Table 1 Day care services (continued)**

Study number	Author(s)	Sample	Care recipient group	Research methods	Intervention	Duration of intervention	Outcomes	Setting
200	Creed <i>et al.</i> (1997)	89 inpatients (52 carers); 90 day patients (51 carers)	Acute psychiatric illness	Quantitative. Randomised controlled trial. Pre-tests; regular follow-up (up to 12 months)	Day hospital vs. routine inpatient care for persons with acute psychiatric illness	Varied	Standard outcome measures: carer distress. Cost-effectiveness	UK
230	Leitsch <i>et al.</i> (2001)	Client–carer pairs (261)	Dementia	Quantitative. No control. Pre-tests; follow-up (3 months). Longer-term follow-up (to discharge)	Adult day service programmes (medical model vs. social model)	Varied	Standard outcome measures: stress. Satisfaction with programme	USA
248	Reifler <i>et al.</i> (1999)	50 sites providing adult day care centres	Selected from those applying to foundation for grants or technical assistance	Case series	Partners in Caregiving (PIC): the Dementia Services Programme (grants vs. technical assistance)	4-year period (1992–1996)	Service use and financial performance	USA

## Services to Support Carers of People with Mental Health Problems

**Table 2 In-home respite care (N = 4)**

Study number	Author(s)	Sample	Care recipient group	Research methods	Intervention	Duration of intervention	Outcomes	Setting
77	Jansson <i>et al.</i> (1998)	Total (67). Carers (25); volunteers (27); deacons (15)	Dementia	Qualitative. No control group. Pre-/post-interviews	'Circle Model': in-home respite and training	4 months	Service evaluation	Sweden
117	Milne <i>et al.</i> (1993)	Carers (78). Study group (63); control (15). Referring agents (numbers not given)	Elderly people (dementia and stroke were the two most common conditions)	Quantitative. Control group. Pre/3-month assessment	Age Concern Carer Support Scheme	Varied	Standard outcome measures: stress, strain, coping. Carer satisfaction questionnaire. Referrer satisfaction form	UK
186	Wishart <i>et al.</i> (2000)	Carers (24). Study (13); control (11)	Cognitive impairment	Mixed. Randomised treatment/controlled trial. Pre-/post-tests	Special Steps: visiting/walking programme	Weekly, for 6 weeks	Standard outcome measures: carer burden, social support; health and social service utilisation. Satisfaction with programme	Canada
214	Gwyther (1989)	Patient-carer pairs (40)	Dementia	Quantitative. No control. Pre-/post tests	In-home respite care	Varied	Satisfaction with service. Other outcomes measures (not described in detail)	USA

## Services to Support Carers of People with Mental Health Problems

**Table 3 Institutional respite (N = 5)**

Study number	Author(s)	Sample	Care recipient group	Research methods	Intervention	Duration of intervention	Outcomes	Setting
4	Goldman <i>et al.</i> (1993)	Parents (c. 32 over 3 years); campers (c.31); graduate students/psychiatry residents (c.7)	Serious mental illness	Quantitative. No control group. No pre-test	Annual 'respite camp' for all family members	One week	Ratings forms: programme/camp evaluation	USA
6	Burdz and Eaton (1988)	Carers (55). Study (35) (15 dementia; 20 non-dementia). Wait list control (20) (12 dementia; 8 non-dementia)	Dementia patients and non-dementia patients	Quantitative. Control. Pre-/post-tests	Respite care programme	2-week respite stay in nursing home	Standard outcome measures: carer burden; assistance; problem behaviours	Canada
50	Larkin and Hopcroft (1993)	Carers (22); patients (21)	Alzheimer's disease	Quantitative. No control group. Pre-/post-tests. Follow up (14 days after discharge)	Hospital respite programme	2-week inpatient stay on 3 monthly basis	Standard outcome measures: carer stress. Carer satisfaction with service; receptivity to long-term inpatient placement.	USA



**Services to Support Carers of People with Mental Health Problems**

**Table 3 Institutional respite (continued)**

Study number	Author(s)	Sample	Care recipient group	Research methods	Intervention	Duration of intervention	Outcomes	Setting
182	Watkins and Redfern (1997)	Patients (34); carers (27)	Dementia	Mixed. Case study approach. No control. Measures within one week of first attendance; then 6 weeks, 12 weeks, 6 months	CREST night nursing service	Varied	Standard outcome measures: coping; anxiety. Service evaluation	UK
189	Geiser <i>et al.</i> (1988)	Patients (14)	Mental illness	Mixed. No control. No pre-/post-tests	Respite care	2–7 day inpatient hospitalisation at 6–8-week intervals	Chart review; subject data from families: impact of respite programme on number of in-patient days; benefits of programme to carer	USA

## Services to Support Carers of People with Mental Health Problems

**Table 4 Mixed-respite care services (N = 15)**

Study number	Author(s)	Sample	Care recipient group	Research methods	Intervention	Duration of intervention	Outcomes	Setting
7	Kosloski and Montgomery (1993)	Carers (72). Study (47); wait list control(25)	Alzheimer's disease.	Quantitative. Control group. Pre-/post-tests	Michigan Model Projects Specialised Respite Care Programme	Varied	Standard outcome measures: carer burden; morale	USA
9	Berry <i>et al.</i> (1991)	Female carers (40): Home care (20); day care (20)	Dementia	Quantitative. No control. Tests at baseline, and 5 subsequent occasions	Home care respite services. Comparator: day care respite services	About 19 hours/week	Standard outcome measures: burden; quality of caring relationship; daily activities; use of time. Satisfaction with programme	USA
10	Lawton <i>et al.</i> (1989)	Carers (632): experimental group (317); control group (315)	Alzheimer's disease and related conditions	Quantitative. Randomised controlled trial. Pre-/post tests	Respite Demonstration Programme (Philadelphia)	12 months	Standard outcome measures: burden/satisfaction; physical health; mental health	USA
39	Koffman and Taylor (1997/8)	Carers (12)	Dementia	Qualitative	Respite care	Varied	Discussion about carers' views on services	UK
64	Kosloski and Montgomery (1992)	Carers (114). Respite users (87); non-users (27)	Alzheimer's disease	Quantitative. Control group. Post-tests	Michigan Model Projects Specialized Respite Care Programme	Varied	Structured questionnaire to evaluate the influence of attitudes on respite use	USA
81	Cotrell (1996)	Carers (100)	Dementia	Qualitative. No control. No pre-/post-tests	Respite services	Not given	Use of respite; preferences for methods of service delivery; perceptions of services	USA

## Services to Support Carers of People with Mental Health Problems

**Table 4 Mixed-respite care services (continued)**

Study number	Author(s)	Sample	Care recipient group	Research methods	Intervention	Duration of intervention	Outcomes	Setting
85	Cox (1997)	Carers (228). Users (123); stoppers (55); non-users (50)	Alzheimer's disease or related disorder	Quantitative. Control. Pre-interviews. Follow-up (6 months)	Respite care	Varied	Standard outcome measures: quality of family relationships; use of services; carer need; problem behaviours; burden; well-being; coping ability; competency	USA
86	Gibbins (1986)	Patients (68); carers (73)	Elderly people with dementia, depression or anxiety	Mixed. No control. Pre-tests. Follow up repeats.	Oundle Community Care Unit (day and night centre).	Varied.	Standard outcome measures: strain; stress; problem behaviours	UK
93	Conlin <i>et al.</i> (1992)	Carers (15); respite users (7); control/non-users (8)	Alzheimer's disease or related dementia	Quantitative. Control group. Pre-/post-tests.	Respite care	Respite of 6–8 hours/day, 2 days/week, for 10 weeks	Standard outcome measures: stress and mood disturbances	USA
153	Strang and Haughey (1998)	Carers (10)	Dementia	Qualitative	Respite services	Varied	Carers' experiences of respite, including acceptability/benefits of services	Canada
154	Cox (1998)	Carers (228); users (123); stoppers (55); non-users (50)	Alzheimer's disease or related disorder	Quantitative. Control. Pre-interviews. Follow-up (6 months)	Respite care	Varied	Standard outcome measures: quality of family relationships; use of services; carer need; problem behaviours; burden; well-being; coping ability; competency	USA
157	Ashworth (2000)	Carers (23)	Not stated, but included Alzheimer's disease	Qualitative. No control. Post-tests only	Respite care	Varied	Semi-structured individual interviews: benefits and problems of respite care	UK

## Services to Support Carers of People with Mental Health Problems

**Table 4 Mixed-respite care services (continued)**

Study number	Author(s)	Sample	Care recipient group	Research methods	Intervention	Duration of intervention	Outcomes	Setting
201	Donaldson and Gregson (1989)	EMI patients (105); 35 intervention (24 carers); 70 controls (29 carers)	Elderly mentally infirm (EMI)	Quantitative. Case series with matched controls. Pre-/post-tests	Family support unit (co-ordinated and flexible community care)	Varied	Costs, benefits and effects of providing care for carers	UK
229	Lawton <i>et al.</i> (1989)	Patient-carer pairs (632). Study group (315): control group (317)	Alzheimer's disease	Quantitative. Randomised controlled trial. Pre-/post tests	Respite Demonstration Programme (Philadelphia)	12 months	Standard outcome measures: burden/satisfactions ; physical health; mental health	USA

## Services to Support Carers of People with Mental Health Problems

**Table 5 Education (N = 29)**

Study number	Author(s)	Sample	Care recipient group	Research methods	Intervention	Duration of intervention	Outcomes	Setting
14	Kahan <i>et al.</i> (1985)	Carers (40): study group (22); wait list/control group (18)	Alzheimer's disease and related disorders	Quantitative. Control group. Pre- and post-tests	Specifically designed group support programme	8 weekly 2-hour sessions	Standard outcome measures: family burden; depression; knowledge of dementia. Programme evaluation	USA
18	Dixon <i>et al.</i> (2001)	Family members (37)	Mental illness	Quantitative. No control. Prospective longitudinal evaluation (follow-up at 6 months). Pre/post-tests	Family-to-Family Education Programme	12 weekly 2–3-hour sessions	Standard outcome measures: burden; empowerment; self-esteem; sense of mastery; social network; depression; physical health	USA
19	Chiverton and Caine (1989)	Carers (40): study group (20); control group (20)	Alzheimer's disease	Quantitative. Control group. Pre-/post-tests	Educational programme	3 sessions of 2 hours	Standard outcome measure: family coping	USA

## Services to Support Carers of People with Mental Health Problems

**Table 5 Education (continued)**

Study number	Author(s)	Sample	Care recipient group	Research methods	Intervention	Duration of intervention	Outcomes	Setting
20	Abramowitz and Coursey (1989)	Carers (48); study group (24); wait list control group (24)	Schizophrenia	Quantitative. Matched controls. Pre-/post-tests	Educational support group	6 weekly 2-hour sessions	Standard outcome measures: trait anxiety; personal distress; negative feelings toward patient; life upset; use of community resources; generalised self-efficacy. Intervention evaluation	USA
30	Peternelj-Taylor and Hartley (1993)	Family/friends (370)	Mentally ill	Quantitative. Self-administered evaluation	'Living with mental illness' workshop for families and friends	One day (8 hours)	Workshop evaluation	USA
43	Mort <i>et al.</i> (1993)	Carers (23)	Dementia	Quantitative. No control group. Pre-/post tests (at 6 months)	Educational programme	Not clear; possibly one session	Structured interview guide focusing on problem behaviours and psychotropic medications	USA
49	Murray <i>et al.</i> (1997)	Carer/patient pairs (44). Study = 26 pairs; control = 18 pairs	Mental illness	Quantitative. Randomised controlled trial. Pre-/post-tests. Follow-up (24-28 weeks)	Individual multidisciplinary packages	Not clear; possibly 12-14 weeks	Standard outcome measures: carer mental health; service usage; social problems	UK

## Services to Support Carers of People with Mental Health Problems

**Table 5 Education (continued)**

Study number	Author(s)	Sample	Care recipient group	Research methods	Intervention	Duration of intervention	Outcomes	Setting
72	Pickett-Schenk <i>et al.</i> (2000)	Families (424)	Mental illness	Quantitative. National survey	Journey of Hope Educational Programme	12 weeks	Evaluation of programme outcomes Satisfaction with programme	USA
75	Toth-Cohen (2000)	Occupational therapists (4)	Dementia	Qualitative	Occupational therapists' support and education for carers in the community	Varied	Therapists' self-perceptions as educators/supporters of carers	USA
76	Steffen <i>et al.</i> (1999)	Carers (51). Telephone survey (35). Focus groups (16) (8 carers; 8 professionals)	Alzheimer's disease and related diseases	Mixed survey and focus groups	How to Cope educational programme	4 weekly 2-hour sessions	Evaluation of programme. Participant satisfaction	USA
80	Zanetti <i>et al.</i> (1998)	Carers (23). Study group (12); control group = 9	Dementia	Quantitative. Control group. Pre-/post-tests. Follow-up (3 months)	Educational programme	6 sessions of one hour	Standard outcome measures: depression; stress; quality of life; knowledge of disease	Italy
102	Birchwood <i>et al.</i> (1992)	Relatives (94). Group (47); post (30); video (17)	Schizophrenia	Quantitative. No control group. Pre-/post tests. Follow-up (6 months)	Three methods of delivering educational interventions: information given in a group; by post; by video	Weekly for 4 weeks	Standard outcome measures: knowledge; beliefs and expectations; stress; burden; patient disturbance; social functioning	UK

## Services to Support Carers of People with Mental Health Problems

**Table 5 Education (continued)**

Study number	Author(s)	Sample	Care recipient group	Research methods	Intervention	Duration of intervention	Outcomes	Setting
113	Reinhard (1994)	Carers (94)	Severe mentally illness	Quantitative. No control group. Post-tests	Provision of information from professionals	Varied	Standard outcome measures: sense of control; depression; carer burden; well-being; professional support; disruptive behaviours	USA
120	Burgener <i>et al.</i> (1998)	Patient-carer pairs. Total intervention = 11 pairs; educational programme = 12 pairs; behavioural intervention programme = 12 pairs; control group = 12 pairs	Alzheimer's disease or related dementia	Quantitative. Control group. Pre-/post-tests (6 months)	Education programme. Comparator: behaviour intervention programme	One session of approx 90 minutes	Standard outcome measures: knowledge of dementia; stress	USA
125	Kuhn and Mendes de Leon (2001)	Carers (58)	Alzheimer's disease (early stages)	Quantitative. No control group. Pre-/post-tests. Follow-up (9 months)	Alzheimer's disease Knowledge Building Programme	5 x 2-hour weekly sessions	Standard outcome measures: knowledge, depression, management of problem behaviours. Programme evaluation	USA



## Services to Support Carers of People with Mental Health Problems

**Table 5 Education (continued)**

Study number	Author(s)	Sample	Care recipient group	Research methods	Intervention	Duration of intervention	Outcomes	Setting
131	Bedard <i>et al.</i> (1997)	Patient-carer pairs (111)	Cognitive impairment	Quantitative. No control. Pre-and post-tests	Standard medical intervention, including education of carers	Short	Standard outcome measures: carer burden; health; time demands from caring; informal social support	Canada
140	Coen <i>et al.</i> (1999)	Carers (32)	Dementia	Quantitative. No control. Pre-/post tests (6 months)	Carer Education Programme	8 weekly 2-hour sessions	Standard outcome measures: quality of life; burden; well-being; patient problem behaviours; informal social support; knowledge of dementia	Ireland
145	Magni <i>et al.</i> (1995)	Carers (22)	Dementia	Quantitative. No control. Pre-/post-tests	Educational programme	8 weekly 2-hour sessions	Standard outcome measures: stress, depression, knowledge	Italy
158	Pratt <i>et al.</i> (1989)	Families (68)	Neurologically impaired elders	Quantitative. Postal survey. No control. Post-test	Legal-Financial Education Workshop	3-hour workshop	Workshop evaluation	USA
159	Matthew (1990)	Carers (32)	Dementia	Mixed (questionnaire and follow-up interviews). No control. Post-test	Community psychiatric nurses as communicators and information providers	Not clear	Evaluation of CPNs' effectiveness in communicating information to carers	UK

## Services to Support Carers of People with Mental Health Problems

**Table 5 Education (continued)**

Study number	Author(s)	Sample	Care recipient group	Research methods	Intervention	Duration of intervention	Outcomes	Setting
160	Farran and Keane-Hagerty (1994)	Carers (139). ESG (62); AASG (19); control group (58)	Dementia	Quantitative. Control group. Pre-/post-tests	Educational Support Group (ESG) Comparator: Alzheimer's Association support group (AASG)	ESG: 8 weekly 2-hour sessions. AASG: 90-minute monthly meetings	Standard outcome measures: carer concerns	USA
162	Russell <i>et al.</i> (1989)	Carers (5)	Dementia	Quantitative. No control. Pre-/post-tests	Relatives Support Group	6 weeks	Standard outcome measures: disturbing behaviours; emotional distress; strain; depression	UK
164	Brooker <i>et al.</i> (1992)	Families (30). Study group (17); control (13)	Schizophrenia	Quantitative. Pre-/post-tests. Follow-up (6 months)	Education about the nature of schizophrenia by community psychiatric nurses.		Standard outcome measures: functional knowledge about schizophrenia	UK
168	Dura (1993)	Carer (1)	Huntington's disease	Quantitative. Pre-/post-tests. Follow up (one month)	Educational intervention	4 2-hour sessions	Standard outcome measures: depression; affective states; confidence in ability to assist; behaviour problems; knowledge. Programme evaluation	USA

## Services to Support Carers of People with Mental Health Problems

**Table 5 Education (continued)**

Study number	Author(s)	Sample	Care recipient group	Research methods	Intervention	Duration of intervention	Outcomes	Setting
272	Smith and Birchwood (1987)	Family members (40). Group condition 20. Postal condition 20	Schizophrenia	Quantitative. No control. Pre-/post-tests. Follow-up (6 months)	Educational intervention delivered in two different formats (by professional in a group; in booklet form through post)	4-weekly sessions	Standard outcome measures: knowledge acquisition; beliefs about schizophrenia and its treatment; worry and fear; behavioural disturbance; stress; family distress	UK
285	Ghatak (1994)	Patients and carers (40 families). Study group (20); control group (16)	Alzheimer's disease and related dementia	Quantitative. Control group. Pre-/post-tests	Educational/training intervention	10 weekly 1-hour sessions	Standard outcome measures: stress; coping with problem behaviours	USA
286	Mullen <i>et al.</i> (1992)	Relatives (13)	Chronic mental illness	Quantitative. No control. Post-test	Workshop	One 90-minute meeting	Questionnaire on impact of workshop on understanding of: service operation; patient problems; caring role	UK
287	Sidley <i>et al.</i> (1991)	Relatives (18). Modified educational package (9); original educational package (9)	Schizophrenia	Quantitative. Pre-/post-tests. No control	'Modified' education package. Comparator: 'original' education package	2 90-minute group sessions	Standard outcome measures: functional value of knowledge of schizophrenia; factual knowledge; stress symptoms; family distress; patient disturbance	UK

## Services to Support Carers of People with Mental Health Problems

**Table 6 Training (N = 21)**

Study number	Author(s)	Sample	Care recipient group	Research methods	Intervention	Duration of intervention	Outcomes	Setting
17	Fisher and Laschinger (2001)	Carers (36)	Alzheimer's disease	Quantitative. No control group. Pre-/post-tests	Relaxation training programme	6 weeks	Standard outcome measures: behavioural problems. Self-efficacy for controlling anxiety	Canada
59	Mitchell (2000)	Carers (7)	Dementia; confused	Quantitative. No control group. Pre-/post-tests	Stress Management Programme	Weekly, for 4 weeks	Standard outcome measures: burden	UK
66	Gendron <i>et al.</i> (1996)	Carers (35). C-B group (18); support group (17)	Dementia	Quantitative. No control. Pre-/post tests. Follow-up (3 and 6 months)	Cognitive-behavioural group intervention C-B). Comparator: support group	8 weekly sessions of 90 minutes	Standard outcome measures: psychological distress; depression; coping; marital adjustment; burden. Programme evaluation questionnaire	Canada

## Services to Support Carers of People with Mental Health Problems

**Table 6 Training (continued)**

Study number	Author(s)	Sample	Care recipient group	Research methods	Intervention	Duration of intervention	Outcomes	Setting
71	Quayhagen and Quayhagen (1989)	Carer-patient dyads (16 pairs). Study group (10 pairs); control group (6 prs)	Alzheimer's disease	Mixed. Control group. Pre-/post-tests	Cognitive stimulation programme implemented by the family in the home setting	One hour per day for 8 months	Standard outcome measures: well-being; burden; anxiety; depression; health	USA
73	Robinson and Yates (1994)	Carers (33). BMSDP (11); SSDP (10); Control group (12)	Alzheimer's disease and related disorders	Quantitative. Control group. Pre-/post tests	Behavioural management development skills Programme (BMSDP). Comparator: social skills development programme (SSDP)	6 90-minute sessions over 12 weeks	Standard outcome measures: carer burden; attitudes towards, and satisfaction with, help and social support; problem behaviours	USA
88	Wright <i>et al.</i> (2001)	Carers (93). Study group (68); control group (25)	Alzheimer's disease	Quantitative. Randomised treatment/control trial. Pre-/post-tests	One year continuum of care education and counselling programme	One year	Standard outcome measures: carer stress; depression; physical health	USA

## Services to Support Carers of People with Mental Health Problems

**Table 6 Training (continued)**

Study number	Author(s)	Sample	Care recipient group	Research methods	Intervention	Duration of intervention	Outcomes	Setting
90	Teri <i>et al.</i> (1997)	Patient–carer pairs (72). BT-PE (23); BT-PS (19). Controls: typical care (10); waiting list (20)	Dementia	Quantitative. Two study groups; two controls. Pre-/post-tests. Follow-up (six months)	Behaviour Therapy Programme emphasising patient-pleasant events (BT-PE). Comparator: Behaviour Therapy Programme to train carers in effective problem solving (BT-PS).	9 weekly 1-hour sessions	Standard outcome measures: carer depression; burden; positive aspects of caring	USA
96	Brodaty <i>et al.</i> (1993)	Patient–carer pairs (96 pairs). Immediate carer training (33). 6-month delayed carer training (32). Patient memory retraining/no training for carers (31)	Dementia	Quantitative. Control group. Pre-/post-tests. Follow-up (to 5 years)	10-day residential care-giver training programme; 10-day memory retraining programme for patients	10 days	Standard outcome measures: carer stress; neuroticism; satisfaction. Impact of training on nursing home admission and/or survival to death	Australia
126	McCurry <i>et al.</i> (1998)	Carers (36). Group treatment (7); individual treatment (14); waiting list/control (15)	Dementia	Quantitative. Control group. Pre-/post-tests. Follow-up (3 months)	Behavioural treatment to reduce sleep problems	Between 4 and 6 weeks	Standard outcome measures: carer sleep; depression; patient behaviours; burden	USA

## Services to Support Carers of People with Mental Health Problems

**Table 6 Training (continued)**

Study number	Author(s)	Sample	Care recipient group	Research methods	Intervention	Duration of intervention	Outcomes	Setting
129	Ripich <i>et al.</i> (1998)	Carers (37). Study group (19); control group (18)	Alzheimer's disease (early–midstage)	Quantitative. Control group. Pre-/post-tests. Follow-up at (6/12 months)	Focused communication training	8 hours over 4 weeks	Standard outcome measures: well-being; depression; health; general hassles; communication hassles; knowledge	USA
135	Corbeil <i>et al.</i> (1999)	Carer–patient pairs (87 pairs). Active cognitive stimulation (28); passive stimulation (28); wait list control (31)	Alzheimer's disease	Quantitative. Control. Pre-/post test at 3 months. Follow-up (9 months)	Active cognitive stimulation. Comparator: passive stimulation	One hour daily for 6 days for 12 weeks, followed by 2 booster contacts in next 6 months	Standard outcome measures: memory and behaviour problems; stress coping; emotional support	USA
144	Brodaty <i>et al.</i> (1997)	Patient–carer pairs (96 pairs). Immediate carer training (33). 6-month delayed carer training (32). Patient memory retraining/no training for carers (31)	Dementia (mild to moderate)	Quantitative. Control group. Pre-/post-tests. Follow-up (to 8 years)	10-day residential care-giver training programme; 10-day memory retraining programme for patients	10 days	Standard outcome measures: carer stress; neuroticism; satisfaction  Impact of training on nursing home admission and/or survival to death	Australia

## Services to Support Carers of People with Mental Health Problems

**Table 6 Training (continued)**

Study number	Author(s)	Sample	Care recipient group	Research methods	Intervention	Duration of intervention	Outcomes	Setting
147	Hinchliffe <i>et al.</i> (1995)	Patient–carer pairs (40). Study group = 22 pairs; waiting list/control = 18	Dementia	Quantitative. Control group. Pre-tests. Re-assessment at 16 and 32 weeks	Individualised packages of care	16 weeks	Standard outcome measures: carer well-being; behavioural disturbances; social support	UK
151	Chang (1999)	Patient–carer pairs (65). Study group (31); attention-only telephone calls (34)	Dementia	Quantitative. Two-group randomised trial. No control. Pre-/post-tests. Follow up (12 weeks)	Cognitive-behavioural intervention Comparator: 'attention-only' telephone calls	8 weeks	Standard outcome measures: coping; burden/satisfaction; emotional and physical health	USA
155	Robinson (1988)	Carers (20). Study group (11); control group (9)	Alzheimer's disease or related disorder	Quantitative. Control group. Pre-/post-tests	Social skills training programme	4 2-hour sessions	Standard outcome measures: Carer burden, self-esteem, social skills, social support. Programme evaluation	USA



## Services to Support Carers of People with Mental Health Problems

**Table 6 Training (continued)**

Study number	Author(s)	Sample	Care recipient group	Research methods	Intervention	Duration of intervention	Outcomes	Setting
179	Seltzer <i>et al.</i> (1992)	Patients and family members (143 pairs). Dementia (58 pairs); haemodialysis (85 pairs)	Elderly patients with dementia (55+ years). Elderly patients needing dialysis (60+ years)	Quantitative. Control group. Pre-/post-tests	Case management training (Family Centred Community Care for the Elderly)	6 months	Standard outcome measures: burden; contact between carer and patient. Counts of: case management tasks performed by family member and social worker; tasks successfully completed; types of tasks performed	USA
180	Kilstoff and Chenoweth (1998)	Total sample (39). Clients (16); carers (16); day care staff (7)	Dementia	Qualitative; action research. In-depth interviews pre-/post treatment	Gentle hand treatment for dementia day care clients using three essential oils	15-minute treatments	In-depth interviews; focus group discussions; client observations logbooks. Evaluation of hand treatment programme	Australia
184	Quayhagen and Quayhagen (1996)	Patient-carer pairs (10 pairs)	Dementia	Qualitative. No control. Pre-/post tests. Follow-up (8 months)	Cognitive remediation intervention	8 fortnightly sessions for 4 months	Efficacy of intervention: interviews; observation, care-giver log recordings; semi-structured evaluation forms	USA

## Services to Support Carers of People with Mental Health Problems

**Table 6 Training (continued)**

Study number	Author(s)	Sample	Care recipient group	Research methods	Intervention	Duration of intervention	Outcomes	Setting
188	Ripich <i>et al.</i> (1999)	Carers (54). FOCUSED study group (22); FOCUSED-Booster study group (10); control group (22)	Alzheimer's disease: early–midstage	Quantitative. Control group. Pre-/post-tests. Follow-up (6/12 months)	FOCUSED communication training. FOCUSED-Booster training	FOCUSED: 8 hours over 4 weeks. FOCUSED-Booster Follow-up: reinforcers at 4 months, 8 months, and 11 months after entry	Communication task (planning a menu); observation of communication	USA
196	Brodaty <i>et al.</i> (1991)	Patient-carer pairs (96 pairs). Immediate carer training (33). 6-month delayed carer training (32). Patient memory retraining/no training for carers = 31	Dementia (mild to moderate)	Quantitative. Control group. Pre-/post-tests. Follow-up (to 3 years)	10-day residential care-giver training Programme; 10-day memory retraining programme for patients	10 days	Standard outcome measures: carer stress; neuroticism; satisfaction Impact of training on nursing home admission and/or survival to death	Australia
273	Brodaty and Gresham (1989)	Patient–carer pairs (96 pairs). Immediate carer training (33). 6-month delayed carer training (32). Patient memory retraining/no training for carers (31)	Dementia: mild to moderate	Quantitative. Control group. Pre-/post-tests. Follow-up (to 3 years)	10-day residential care-giver training programme; 10-day memory retraining programme for patients	10 days	Standard outcome measures: carer stress; neuroticism; satisfaction. Impact of training on nursing home admission and/or survival to death	Australia

## Services to Support Carers of People with Mental Health Problems

**Table 7 Psychoeducational interventions (N = 23)**

Study number	Author(s)	Sample	Care recipient group	Research methods	Intervention	Duration of intervention	Outcomes	Setting
2	Pakenham and Dadds (1987)	Parents (7)	Schizophrenia (18–40 years)	Quantitative. No control group. Pre-/post-tests	Supportive/ educational programme	9 weekly sessions of 2 hours	Standard outcome measures: knowledge; behavioural disturbances; psychological health; coping. Consumer needs questionnaire	Australia
5	Buckwalter <i>et al.</i> (1999)	Carers (240). Study (132); comparison (108)	Alzheimer's disease and related dementias	Quantitative. Pre-/post-tests (at 3–6 months). Follow-up (12 months)	Community-based psycho-educational-nursing intervention. Comparator: routine support	6 months	Standard outcome measures: carer affect, depression	USA
16	Hepburn <i>et al.</i> (2001)	Families (117). Study group (72); wait list control (45)	Dementia (mild–severe)	Quantitative. Control group. Pre-/post-tests. Follow-up (5 months)	Care-giver role training (Minnesota Family Workshop)	2-hour sessions for 7 weeks	Standard outcome measures: depression, burden, problem behaviours	USA
21	Bland and Harrison (2000)	Carers (15)	Bipolar disorder	Quantitative. No control. Pre-/post tests. Follow-up (3 months)	Psycho-educational programme	Not clear	Standard outcome measures: knowledge; distress; social support; coping; attribution of cause of symptoms. Programme evaluation	Australia

## Services to Support Carers of People with Mental Health Problems

**Table 7 Psychoeducational interventions (continued)**

Study number	Author(s)	Sample	Care recipient group	Research methods	Intervention	Duration of intervention	Outcomes	Setting
22	Hugen (1993)	Family members (22)	Schizophrenia	Quantitative. No control group. Pre-/post-tests	Educational workshop	One day	Standard outcome measures: knowledge; attitudinal change.  Relapse rates.  Satisfaction with workshop	USA
23	Honig (1997)	Patient–carer pairs: 52. Study group (29) pairs; wait list/control group (23) pairs	Bipolar disorder	Quantitative. Control group. Pre-/post-tests	Multi-family psycho-educational intervention	6 2-hour sessions	Standard outcome measures: EE levels. Programme evaluation questionnaire	Netherlands
48	Ostwald <i>et al.</i> (1999)	Families (117); study group (72); wait list control (45)	Dementia (mild to severe)	Quantitative. Control group Pre-/post-tests. Follow up (5 months)	Psycho-educational family group intervention (Minnesota Family Workshop)	2 hours sessions for 7 weeks	Standard outcome measures: depression, burden, problem behaviours	USA
54	Mannion <i>et al.</i> (1994)	Carers (19)	Serious mental illness	Quantitative. No control. Pre-/post-tests. Follow-up (12 months)	Group psychoeducational approach for spouses.	2-hour meetings over 10 weeks	Standard outcome measures: knowledge; personal distress; attitudes; coping	USA

## Services to Support Carers of People with Mental Health Problems

**Table 7 Psychoeducational interventions (continued)**

Study number	Author(s)	Sample	Care recipient group	Research methods	Intervention	Duration of intervention	Outcomes	Setting
55	Hosaka and Sugiyama (1999)	Carers (20).	Dementia	Quantitative. No control. Pre-/post-tests	Structured intervention group	5 weekly sessions of 90 minutes	Standard outcome measures: psychological and physical health. Blood samples	Japan
56	Gallagher-Thompson and DeVries (1994)	Carers (48)	Alzheimer's disease or related dementia	Quantitative. Part of a larger study. Pre-/post-tests; follow-up (18 months)	Anger management class (one component of psychoeducational programme)	2 hours for 8 weeks + 2 booster sessions	Standard outcome measures: carer stress, burden, negative effect	USA
58	McFarland and Sanders (2000)	Carers (11)	Alzheimer's disease	Qualitative. No control	Educational support groups for male carers.	One weekday evening for 4 weeks	Evaluation of group process and format in relation to accomplishment of group objectives	USA
68	Sherrill <i>et al.</i> (1997)	Family members (182); patients (132)	Elderly patients with recurrent major depression	Quantitative. No control. Pre-/post-measures (for patients only)	Family psychoeducational workshop	One day	Evaluation of content and quality of workshop	USA
69	Zhang <i>et al.</i> (1998)	Carers (1048). Study group (682); control group (366)	Schizophrenia	Quantitative. Control group. Pre-/post-tests. Follow-up (2 years)	Group psychoeducational programme	10 sessions in year 1; 4 in year 2	Standard outcome measures: burden, mental and physical health status, knowledge of caring	China

## Services to Support Carers of People with Mental Health Problems

**Table 7 Psychoeducational interventions (continued)**

Study number	Author(s)	Sample	Care recipient group	Research methods	Intervention	Duration of intervention	Outcomes	Setting
70	Cummings <i>et al.</i> (1998)	Carers (13)	Early stage Alzheimer's disease	Quantitative. No control group. Pre-/post-measures	Psychoeducational support group	8 weekly sessions of 90 minutes	Standard outcome measures: stress, adaptive functioning; competency and self-confidence; beliefs about caring role; coping behaviours	USA
79	Cummings (1996)	Carer case examples (4)	Early stage Alzheimer's disease	Not given (but see study no 70 above)	Psychoeducational support group	Eight weekly sessions of 90 minutes	Not given (but see study no 70 above)	USA
87	Woods <i>et al.</i> (1998)	Carers (104) ANS (55); CPN/CMHT (49); Admiral Nurses and CPNs; Team leaders	Dementia	Mixed. No control. Pre-/post-tests (at 8 months)	Admiral Nurse Service (ANS). Comparator: CPN/Community Teams for Mental Health for Older People	8 months	Standard outcome measures: quality of relationship; strain and distress; behavioural problems; need. Service questionnaire: frequency and satisfaction	UK
104	Solomon and Draine (1995)	Family members (225). Individual consultation (66); group family workshop (67); waiting list control group (92)	Schizophrenia or major affective disorder	Quantitative. Random assignment to study conditions or control group. Pre-/post-tests. Follow-up (6 months)	Individual Family Consultation. Comparator: Group Family Workshop	3 months	Standard outcome measures: burden; patient's level of functioning; social support, self-efficacy; satisfaction with coping	USA

## Services to Support Carers of People with Mental Health Problems

**Table 7 Psychoeducational interventions (continued)**

Study number	Author(s)	Sample	Care recipient group	Research methods	Intervention	Duration of intervention	Outcomes	Setting
105	North <i>et al.</i> (1998)	Relatives/patients (80). Family workshops (56); multiple family groups (24)	Schizophrenia	Quantitative. No control. Pre-/post-tests	Multifamily Psychoeducational Programme	Family workshops: 4 one-day events, over 2 years. Family groups: 90- minute meetings twice monthly in first year; once every 3 months in second year	Standard outcome measures: ability to manage; knowledge; disruptions to family life. Hospital admissions/days. Number of days lost from work. Satisfaction questionnaire	USA
106	Solomon <i>et al.</i> (1997)	Family members (225). Individual consultation (66); group family workshop (67); wait list control (92)	Schizophrenia or major affective disorder	Quantitative. Random assignment to study conditions or control group. Pre-/post-tests. Follow-up (6 months)	Individual Family Consultation. Comparator: Group Family Workshop	3 months	Standard outcome measures: burden; patient's level of functioning; social support, self-efficacy; satisfaction with coping	USA
107	Posner <i>et al.</i> (1992)	Family members (55). Study group (28); wait list/control (27)	Schizophrenia (patients 40 years of age or younger)	Quantitative. Control group. Pre-/post-tests. Follow-up (6 months)	Family psychoeducational support group	8 weekly sessions of 90 minutes	Standard outcome measures: knowledge of schizophrenia; family satisfaction; negative feelings for patient; coping behaviours; psychological distress. Consumer satisfaction with health care services	USA

## Services to Support Carers of People with Mental Health Problems

**Table 7 Psychoeducational interventions (continued)**

Study number	Author(s)	Sample	Care recipient group	Research methods	Intervention	Duration of intervention	Outcomes	Setting
141	Haupt <i>et al.</i> (2000)	Patient–carer pairs (14).	Dementia	Quantitative. No control. Pre-/post-tests	Psychoeducational group intervention	12 weekly meetings of 90 minutes	Standard outcome measures: problem behaviours; carer burden	Germany
148	Brodaty <i>et al.</i> (1994)	Carers (81). Completers group (33); Non-/partial completers (22); control group (26). Co-ordinators = 21	Dementia	Mixed. Control. Pre-/post-tests	Group education programme	18 hours over 4 months	Standard outcome measures: carer burden; psychological stress; satisfaction with life; well-being; knowledge	Australia
174	Shimodera <i>et al.</i> (2000)	Pts (87); high-EE (38); low-EE (49). Close family members (111). SES + SFT group (13) pts/families. SES group (17 pts/families)	Schizophrenia	Quantitative. High-EE families randomly allocated to SES or SES+ SFT. Pre-/post-tests. Follow-up (9 months	Short education sessions (SES) in high-EE households. Comparator: short education sessions + single-family treatment in high-EE households	Once every 2 weeks for 9 months	Standard outcome measures: EE. Risk of relapse	Japan



## Services to Support Carers of People with Mental Health Problems

**Table 8 Family interventions (N = 20)**

Study number	Author(s)	Sample	Care recipient group	Research methods	Intervention	Duration of intervention	Outcomes	Setting
40	Barrowclough <i>et al.</i> (1999)	Patient–carer pairs (77 pairs). Study group (38); control group (39)	Schizophrenia	Quantitative. Randomised controlled pragmatic trial. Pre-/post-tests	Needs-based cognitive–behavioural family intervention	24 weeks	Standard outcome measures: cardinal needs; psychological distress; depression; social behaviour	UK
60	Mitrani and Czaja (2000)	Carers (224), assigned to one of two study conditions or control group	Dementia	Quantitative. Randomised controlled trial	Family-based therapy (SET). Comparator: SET + computer integrated telephone system	12 months	Family interactional patterns	USA
92	Weinberg and Huxley (2000)	Carers (62). FSWs (15); co-professionals (15)	Schizophrenia	Mixed. No control. Post-test only	FSWs	Varied	Standard outcome measures: quality of life; burden. Diary study of activities undertaken by FSWs. Co-professionals' evaluation of/satisfaction with FSWs	UK
99	McCreadie <i>et al.</i> (1991)	Carers (31)	Schizophrenia	Quantitative. No control. Pre-/post tests. Follow-up (18 months)	Treatment package (educational seminars; relatives' groups; family meetings)	Varied	Standard outcome measures: EE. Relapse rates	UK
101	Leff <i>et al.</i> (1990)	Relatives (23 families). Family therapy + education (12). Relatives group + education (11)	Schizophrenia	Quantitative. No control group. Pre-/post-tests. Follow-up (2 years)	Family therapy in the home + education. Comparator: relatives group + education	Family therapy: fortnightly, for 9 months	Standard outcome measures: EE; knowledge. Time budgets. Relapse rates	UK

## Services to Support Carers of People with Mental Health Problems

**Table 8 Family interventions (continued)**

Study number	Author(s)	Sample	Care recipient group	Research methods	Intervention	Duration of intervention	Outcomes	Setting
103	Falloon and Pederson (1985)	Patients (36); parents (56). Family management group (18). Individual management group= 18	Schizophrenia	Quantitative. No control group. Testing at baseline and pre-determined intervals over 2 years	Family management of schizophrenia. Comparator: individual management	24 months	Standard outcome measures: psychopathology, social adjustment, family distress and burden; family coping functions	UK
108	Xiong <i>et al.</i> (1994)	Families (63). Study group (34); control group (29)	Schizophrenia	Quantitative. Control group. Pre-/post-tests. Follow-up (18 months)	Family-based intervention	1–2 years	Standard outcome measures: family burden. Number and duration of hospitalisations	China
109	Leff <i>et al.</i> (1989)	Relatives (23 families). Family therapy + education (12). Relatives group + education (11)	Schizophrenia	Quantitative. No control group. Pre-/post-tests	Family therapy in the home+ education. Comparator: relatives group + education	Family therapy: fortnightly, for 9 months	Standard outcome measures: EE; knowledge. Time budgets. Relapse rates	UK
110	MacCarthy <i>et al.</i> (1989)	Patients/relatives (26 families). Study group (9); control group (17)	Severe mental illness	Quantitative. Control group. Pre-/post-tests	Interactive education sessions at home, followed by monthly relatives group	One year	Standard outcome measures: EE, burden, coping, knowledge	UK
112	Budd and Hughes (1997)	Relatives (20)	Schizophrenia	Qualitative. No control. Post-test only	Clinically based family intervention programme	Average 12 months	Semi-structured interviews: programme evaluation to identify helpful and unhelpful aspects	UK

## Services to Support Carers of People with Mental Health Problems

**Table 8 Family interventions (continued)**

Study number	Author(s)	Sample	Care recipient group	Research methods	Intervention	Duration of intervention	Outcomes	Setting
116	Bentley (1990)	Patients (4); carers (4)	Schizophrenia	Quantitative. No control. Pre-/post tests. Follow-up (6 weeks)	In-home educational and skills training Programme	Twice weekly sessions for 5 weeks	Standard outcome measures: attitudes, family stress	USA
137	Hughes <i>et al.</i> (1996)	Presents 3 case studies	Serious mental illness	Not given	STEP family intervention	Average 12 months	Subjective ratings by therapists; case notes	UK
165	Razali <i>et al.</i> (2000)	Patients and carers (143). Study (CMFT) group (74); control group (BFT) (69)	Schizophrenia	Quantitative. Randomised controlled trial. Pre-/post-tests at 6 months. Follow-up (12 months)	Culturally Modified Family Therapy (CMFT). Comparator: Behavioural Family Therapy (BFT)	12 months	Standard outcome measures: family burden; psychosocial functioning; behavioural difficulties. Number of rehospitalisations .	Malaysia
172	Marley (1992)	Patients/ families (2)	Mentally ill	Qualitative	Family therapy intervention	Not stated	Effectiveness of intervention	USA
261	Tarrier <i>et al.</i> (1991)	Carers (73); high EE study group (25); high EE control group (29); low EE control group (19)	Schizophrenia	Quantitative. Control group. Pre-/post-tests	9-month family intervention. Comparator: short educational programme or routine care	9 months	Relapse rate in patients	UK
263	Van Minnen (1997)	Patients (50). Outreach treatment (25); hospital care/control (25)	Serious mental illness	Quantitative. Randomised controlled trial. Pre-/post tests.	Outreach treatment. Comparator: hospital care	28 weeks	Standard outcome measures: family burden. Hospital admissions	Netherlands

## Services to Support Carers of People with Mental Health Problems

**Table 8 Family interventions (continued)**

Study number	Author(s)	Sample	Care recipient group	Research methods	Intervention	Duration of intervention	Outcomes	Setting
271	Szmukler <i>et al.</i> (forthcoming)	Carers (77). Study results based on sub-group (61). Study group (30); control group (31)	Psychotic disorder	Quantitative. Exploratory randomised controlled trial. Baseline tests; follow-up (16 months)	Family sessions, followed by relatives' groups	9 months	Standard outcome measures: psychological morbidity; appraisal of caring; coping; social support	UK
274	Cardin <i>et al.</i> (1985)	Patients (36). Family management (18); individual management (18)	Schizophrenia	Quantitative. Randomised controlled trial. Pre-/post-tests	Family management. Comparator: individual supportive management	24 months	Standard outcome measures: family burden; carer satisfaction	USA
275	Kuipers <i>et al.</i> (1989)	Presents three case studies (but see study no. 110 above)	Severe mental illness	See study no. 110 above	Interactive education sessions at home, followed by a monthly relatives group	One year	Standard outcome measures: EE, burden, coping, knowledge	UK
289	Sellwood <i>et al.</i> (2001)	Patient-carer pairs (77 pairs). Study group (38); control group (39)	Schizophrenia	Quantitative. Follow-up of randomised controlled pragmatic trial (see study no. 40 above). Pre-/post-tests. Follow-up (12 months)	Needs-based cognitive-behavioural family intervention	24 weeks	Standard outcome measures: EE; burden. Longer-term effectiveness of intervention	UK

## Services to Support Carers of People with Mental Health Problems

**Table 9 Mutual support and social activity groups (N = 18)**

Study number	Author(s)	Sample	Care recipient group	Research methods	Intervention	Duration of intervention	Outcomes	Setting
3	Gonyea (1989)	Support group leaders (47). Support group members (301)	Alzheimer's disease	Quantitative. No control group. Post-test	Alzheimer's disease support groups	Varied	Questionnaire survey: strengths and weaknesses of support groups	USA
8	Norton <i>et al.</i> (1993)	Carers (99). Study group (40); control/non-AMI members (59)	Schizophrenic and bi-polar disorders	Quantitative. Control (non-members) group. Post-test	AMI self-help/advocacy group	Varied	Standard outcome measures: costs and benefits of AMI membership	USA
11	Hebert <i>et al.</i> (1994)	Carers (41); study group (23); control group (18)	Dementia	Quantitative. Randomised controlled trial. Pre-/post-tests. Follow-up (8 months)	Specially designed support group programme	8 weekly 3-hour sessions	Standard outcome measures: burden; knowledge; problem behaviours; health care utilisation. Satisfaction with programme	Canada
12	Hebert <i>et al.</i> (1995)	Carers (45); study group (24); control group (21)	Dementia	Follow-up of earlier study (see study no 11 above). Survival analysis	Specially designed support group programme	8 weekly 3-hour sessions	Impact of support group of institutionalisation of patient	Canada
13	Cook <i>et al.</i> (1999)	Carers (120); study (86); control (34)	Mental illness	Quantitative. Control group. Post-test	NAMI-affiliated support groups	Varied	Standard outcome measures: parental burden; depression; social support; service utilisation	USA
15	Gage and Kinney (1995)	Carers (79): attendees group (27); non-attendees group (52)	Dementia	Quantitative. Control (non-attendees) group. Post-test	Carer support groups	Varied	Standard outcome measures: hassles appraisals, coping efforts, well-being	USA

## Services to Support Carers of People with Mental Health Problems

**Table 9 Mutual support and social activity groups (continued)**

Study number	Author(s)	Sample	Care recipient group	Research methods	Intervention	Duration of intervention	Outcomes	Setting
42	Winefield and Harvey (1995)	Carers (36) divided into 3 groups (pilot, treatment and waiting list control)	Chronic schizophrenia	Quantitative. Control group. Pre-/post-tests. Follow-up (8 weeks)	Discussion group	8 weekly meetings	Standard outcome measures: social support; psychological state; attitudes to the patient. Group evaluation	Australia
44	Molinari <i>et al.</i> (1994)	Carers (136). Support group attendees (96); non-attendees (40)	Alzheimer's disease	Quantitative. Control group. Post-test only	Alzheimer's Association open-ended family support groups	Varied	Questionnaire: perceptions of support groups	USA
51	Karlin <i>et al.</i> (1999)	Carers (51) 'nevers' (13); 'formers' (21); 'currents' (17)	Alzheimer's disease	Eight year follow-up of carers participating in earlier (quantitative) study	Alzheimer's disease support group.	Not given	Standard outcome measures: burden; emotional support	USA
65	Haley <i>et al.</i> (1987)	Carers (40). Support group (14). Support/skills group (17); wait list control (9)	Elderly demented patients	Quantitative. Control group. Pre-/post-tests	Support Group. Comparator: support/skills group	10 sessions of 90 minutes	Standard outcome measures: depression, life satisfaction, social activity. Group evaluation	USA
82	Bouricius <i>et al.</i> (1994)	Carers (114)	Mental illness	Quantitative. No control group. Post-test	AMI family support groups	Varied	Survey: perceptions of collaboration between members and professionals	USA
89	Acton and Miller (1996)	Carers (26)	Dementia	Mixed. No control group. Pre-/post-tests	Theory-based support group	One hour, bi-weekly, for 12 months	Standard outcome measures: basic needs	USA
91	Cuijpers <i>et al.</i> (1996)	Carers (110)	Dementia	Mixed. No control group. Pre-/post-tests. Follow-up (6 months)	Support groups	Not given	Standard outcome measures: burden; mental health; social support	Netherlands

## Services to Support Carers of People with Mental Health Problems

**Table 9 Mutual support and social activity groups (continued)**

Study number	Author(s)	Sample	Care recipient group	Research methods	Intervention	Duration of intervention	Outcomes	Setting
122	Forde and Pearlman (1999)	Not given	Alzheimer's disease or related dementia	Observation and informal evaluation	Breakaway programme	Varied	Impact of programme. Programme satisfaction	USA
123	Haley (1989)	Carers (48)	Elderly demented patients	Quantitative. Control group. Pre-/post-tests. Follow-up (average 29 months)	Support Group. Comparator: support/skills group	10 sessions of 90 minutes	Standard outcome measures: depression, life satisfaction, social activity. Additional questions about death/institutionalisation	USA
161	Carson and Manchershaw (1992)	Carers (10)	Chronic mental illness	Quantitative. No control. Post-test	Relatives Support Group	Monthly sessions of 2 hours	One page questionnaire: usefulness of group	UK
173	Winefield <i>et al.</i> (1998)	Carers (36) divided into 3 groups (pilot, treatment and waiting list control)	Chronic schizophrenia	Quantitative. Control group. Pre-/post tests. Follow-up (8 weeks)	Discussion group	8 sessions	Standard outcome measures: social support; psychological state; attitudes to the patient. Group evaluation	Australia

## Services to Support Carers of People with Mental Health Problems

**Table 10 Counselling (N = 9)**

Study number	Author(s)	Sample	Care recipient group	Research methods	Intervention	Duration of intervention	Outcomes	Setting
45	Mittleman <i>et al.</i> (1995)	Carers (206). Study (103); control (103)	Alzheimer's disease	Quantitative. Randomised treatment/control trial. Pre-/post-tests. Long-term follow-up (to 8 years)	Comprehensive support programme	6 sessions of counselling, followed by a weekly, continuous support group. Ongoing counselling available.	Standard outcome measures: carer depression; health; social support	USA
46	Mittleman <i>et al.</i> (1993)	Carers (206). Study (103); control (103)	Alzheimer's disease	Quantitative. Randomised treatment/control trial. Pre-/post-tests. Long-term follow-up (to 8 years)	Comprehensive support programme	6 sessions of counselling, followed by a weekly, continuous support group. On-going counselling available	Standard outcome measures: carer burden; health; social support. Prevention of nursing home placement	USA
47	Mittleman <i>et al.</i> (1996)	Carers (206). Study (103); control (103)	Alzheimer's disease	Quantitative. Randomised treatment/control trial. Pre-/post-tests. Long-term follow-up (to 8 years)	Comprehensive support programme	6 sessions of counselling, followed by a weekly, continuous support group. Ongoing counselling available	Standard outcome measures: carer depression; health; social support. Prevention of nursing home placement	USA
67	Whitlatch <i>et al.</i> (1991)	Carers (113)	Dementia	Reanalysis of data from earlier study (see study no. 95) using prediction analysis	Individual and family counselling. Comparator: support group	8 sessions	Standard outcome measures: carer stress; burden; managing problem behaviour	USA



## Services to Support Carers of People with Mental Health Problems

**Table 10 Counselling (continued)**

Study number	Author(s)	Sample	Care recipient group	Research methods	Intervention	Duration of intervention	Outcomes	Setting
74	Szmukler <i>et al.</i> (1996)	Carers (63). Study group (32); control group (31)	Schizophrenia/schizoaffective psychosis	Quantitative. Randomised treatment/control trial. Pre-/post-tests. Follow-up (6 months)	Individual family counselling programme	6 weekly one-hour sessions	Standard outcome measures: carer physical and mental health; appraisal of caring; coping	Australia
95	Zarit <i>et al.</i> (1987)	Carers (119). Counselling (36). Support group (44). Waiting list/control (39)	Dementia	Quantitative. Randomised treatment/ control trial. Pre-/post-tests. Follow-up (one year)	Individual and family counselling. Comparator: support groups	8 sessions	Standard outcome measures: carer stress; burden; managing problem behaviour.  Evaluation of intervention	USA
115	Sutcliffe and Larnar (1988)	Carers (15). Information group (4). Emotional support (6). Control group (5)	Elderly people with dementia	Quantitative. Pre-/post-tests. Follow-up (12 weeks)	Information group. Comparator: Emotional support. (in-home)	6 weekly 45-minutes home visits	Standard outcome measures: carer mood, stress, health; burden, knowledge	UK
207	Ferris <i>et al.</i> (1987)	Carers (41)	Alzheimer's disease	Quantitative. No control. Pre-/post-tests	Enhanced counselling programme	6 months	Standard outcome measures: carer health. Programme evaluation	USA
249	Roberts (1999)	Carers (77); study (38); control (39)	Cognitively impaired	Quantitative. Randomised treatment/control trial pre-/post-test. Follow-up (6 and 12 months)	Individualised problem-solving counselling by nurses	10 sessions	Standard outcome measures: psychosocial adjustment to illness; carer burden; social support; coping; use of health and social services	Canada

## Services to Support Carers of People with Mental Health Problems

**Table 11 Telephone and computer-based services (N = 16)**

Study number	Author(s)	Sample	Care recipient group	Research methods	Intervention	Duration of intervention	Outcomes	Setting
25	Goodman (1990)	Carers (40). Network-lecture sequence (22); lecture-network sequence (18)	Alzheimer's disease	Quantitative. Random assignment. No control group. Pre-/post-tests	Care-Line: model self-help telephone	12 weeks	Standard outcome measures: problem behaviours; burden; mental health; knowledge; satisfaction with supports for caring; social support; family and friend support	USA
26	Brennan (1993)	Carers (96). Study group (47); control group (49)	Alzheimer's disease	Quantitative. Randomised controlled trial. Pre-/post-tests	ComputerLink (specialised computer network)	12 months	Standard outcome measures: social isolation, depression, caregiving strain, health status, social well-being, social roles. Service utilisation	USA
38	Coyne (1991)	Carer respondents (104)	Alzheimer's disease and other dementias	Quantitative. No control. Post-tests	Statewide toll-free telephone help-line specialising in AD and related dementias	Varied	Specially developed questionnaire: usage patterns; relationship with patient; health status; access to information about services	USA

## Services to Support Carers of People with Mental Health Problems

**Table 11 Telephone and computer-based services (continued)**

Study number	Author(s)	Sample	Care recipient group	Research methods	Intervention	Duration of intervention	Outcomes	Setting
62	Goodman and Pynoos (1990)	Carers (66). Network component (31); lecture component (35)	Alzheimer's disease	Quantitative. Random assignment. No control group. Pre-/post-tests	Care-Line: model self-help telephone	12 weeks	Standard outcome measures: problem behaviours; burden; mental health; knowledge; satisfaction with supports for caring; social support; family and friend support	USA
63	Davis (1998)	Carers (17)	Dementia (mild to severe)	Quantitative. No control. Pre-/post-tests	Telephone-based support and skill training	12 weeks	Standard outcome measures: behavioural problems; problem-solving; social support; depression; life satisfaction	USA
94	Bass <i>et al.</i> (1998)	Carers (96); study group (47); control group (49)	Alzheimer's disease	Quantitative. Randomised controlled trial. Pre-/post-tests	ComputerLink (specialised computer network)	12 months	Standard outcome measures: carer strain (physical, emotional, relationship, activity restriction). ComputerLine usage	USA

## Services to Support Carers of People with Mental Health Problems

**Table 11 Telephone and computer-based services (continued)**

Study number	Author(s)	Sample	Care recipient group	Research methods	Intervention	Duration of intervention	Outcomes	Setting
97	Brennan (1993)	Persons living with AIDS (51); study group (25); control group (26). Alzheimer's disease (96); study group (47); control group = 49	AIDS; Alzheimer's disease	Quantitative. Randomised controlled trial. Pre/post-tests	ComputerLink (specialised computer network)	PwA: 6 months. Alzheimer's disease carers: 12 months	Use patterns	USA
98	Brennan and Smyth (1994)	Carers (47)	Alzheimer's disease	Quantitative. Randomised controlled trial. Pre-/post-tests	ComputerLink (specialised computer network)	12 months	Specially developed instrument on attitudes toward ComputerLink. Rates of usage	USA
133	Brennan <i>et al.</i> (1991)	Carers (22). Control group (numbers not stated)	Alzheimer's disease	Quantitative. Randomised controlled trial. Pre-/post-tests	ComputerLink (specialised computer network )	Varied	Indicators of use over 7-day period. Content analysis of messages	USA
134	Brennan <i>et al.</i> (1992)	Carers (96). Study group (47); control group (49)	Alzheimer's disease	Quantitative. Randomised controlled trial. Pre-/post-tests	ComputerLink (specialised computer network)	Varied	Standard outcome measures: decision-making confidence and skill; isolation. Usage data	USA
136	Skipwith (1994)	Carers (4)	Elderly (diagnosis included cognitive impairment)	Not clear. No control group	Telephone counselling	Tri-weekly, 15-minute phone sessions.	Self-reports: efficacy of short-term telephone counselling	USA

## Services to Support Carers of People with Mental Health Problems

**Table 11 Telephone and computer-based services (continued)**

Study number	Author(s)	Sample	Care recipient group	Research methods	Intervention	Duration of intervention	Outcomes	Setting
152	McClendon <i>et al.</i> (1998)	Carers (96). Study group = 47; control group = 49	Alzheimer's disease	Quantitative. Randomised controlled trial. Pre-/post-tests	ComputerLink (specialised computer network)	12 months	Standard outcome measures: social isolation, depression, caregiving strain, health status, social well-being, social roles. ComputerLink use. Support group use. Attitudes towards Computerlink. Service usage. Monitoring of access to Computerlink	USA
170	White and Dorman (2000)	Messages to mailgroup (532)	Alzheimer's disease	Content analysis.	Internet Alzheimer Mailgroup	20 days	Content and themes of messages posted on a mailgroup	USA
242	Payton <i>et al.</i> (1995)	Carers (96). Study group (47); control group (49)	Alzheimer's disease	Quantitative. Randomised controlled trial. Pre-/post-tests	ComputerLink (specialised computer network)	12 months	Institutionalisation rate	USA
284	Strawn and Hester (1998)	Carers (14)	Dementia	Quantitative. No control. Pre-/post-tests. Follow-up (2 weeks)	Telecare (telephone intervention)	12 week	Standard outcome measures: burden. Utility of a telephone intervention. Carer satisfaction.	USA

**Services to Support Carers of People with Mental Health Problems**

**Table 11 Telephone and computer-based services (continued)**

Study number	Author(s)	Sample	Care recipient group	Research methods	Intervention	Duration of intervention	Outcomes	Setting
288	Brennan <i>et al.</i> (1995)	Carers (96). Study group (47); control group (49)	Alzheimer's Disease	Quantitative. Randomised controlled trial. Pre-/post-tests	ComputerLink (specialised computer network)	12 months	Standard outcome measures: decision-making confidence and skill; social support; burden; depression; carer contact with services	USA

## Services to Support Carers of People with Mental Health Problems

**Table 12 Domiciliary care services (N = 4)**

Study number	Author(s)	Sample	Care recipient group	Research methods	Intervention	Duration of intervention	Outcomes	Setting
124	Vernooij-Dassen <i>et al.</i> (2000)	Patient–carer pairs (49)	Alzheimer’s disease or related dementia	Secondary data analysis of earlier randomised control trial	Support Programme provided by home helps	4 hours/week for 10 months	Standard outcome measures: sense of competence; neuroticism; social support. Number of patient admissions to institutional care	Netherlands
130	Riordan and Bennett (1998)	Patient–carer pairs (38 pairs). Study group= 19; control group= 19	Dementia	Quantitative. Matched pairs. Pre-/post-tests. Follow-up (18 months)	Augmented Dementia Support Service	12 months	Standard outcome measures: psychological distress; coping; problems. Quality and satisfaction questionnaire	UK
269	Winter (2000)	Not clear	Dementia	Quantitative. Case study with matched controls	Personal support worker. Comparator: traditional domiciliary services		Carer satisfaction	UK
283	Whitby <i>et al.</i> (199)	Not given	Elderly confused	Quantitative. No control. Post-test only	Support and Stay (SaS) community service	Not clear	Survey: carers’ perceptions of ability of continue to care without the SaS service	UK

## Services to Support Carers of People with Mental Health Problems

**Table 13 Physical Environment (N = 3)**

Study number	Author(s)	Sample	Care recipient group	Research methods	Intervention	Duration of intervention	Outcomes	Setting
178	Pynoos and Ohta (1991)	Patient –carer pairs (25 pairs)	Alzheimer's disease	Quantitative. No control. Baseline test. Follow-up (7 months)	In-home interventions	Not given	Standard outcome measures: problems and barriers; home environment	USA
183	Gitlin <i>et al.</i> (2001)	Carers (171). Study (93); control (78)	Dementia	Quantitative. Randomised control led trial. Baseline; Follow-up (3 months)	Home environmental intervention	5 90-minute home visits over 3 months	Standard outcome measures: carer well-being (self-efficacy and upset in managing dementia behaviours)	USA
187	Corcoran and Gitlin (1992)	Case example of one carer	Dementia	Case vignette of one carer	Home-based occupational therapy/environmental intervention	5 90-minute home visits over 3 months	Developing and implementing effective environmental strategies	USA



## Services to Support Carers of People with Mental Health Problems

**Table 14 Supporting Carers through Memory Clinics (N = 2)**

Study number	Author(s)	Sample	Care recipient group	Research methods	Intervention	Duration of intervention	Outcomes	Setting
138	Logiudice <i>et al.</i> (1999)	Patient–carer pairs (50). Memory clinic (25 pairs); control (25 pairs)	Cognitive impairment: mild to moderate	Quantitative. Randomised controlled trial. Pre-tests. Follow-up (6 and 12 months)	Memory clinic	2 sessions at memory clinic	Standard outcome measures: burden; psychological distress; psychosocial health-related quality of life; problem behaviours; knowledge. Service utilisation; use of carer groups	Australia
190	Moniz-Cook <i>et al.</i> (1998)	Patient–carer pairs (30 pairs); Study (15); control (15). Key workers	Dementia	Mixed. Control. Pre-/post-tests. Follow-up (18 months)	Early intervention in a memory clinic	6–12 hours, over 4–14 weeks	Standard outcome measures: well-being; psychological distress; depression; anxiety. Service usage	UK

## Services to Support Carers of People with Mental Health Problems

**Table 15 Multidimensional approaches to caring interventions (N = 15)**

Study number	Author(s)	Sample	Care recipient group	Research methods	Intervention	Duration of intervention	Outcomes	Setting
29	Mohide <i>et al.</i> (1990)	Carer–patient dyads (60 pairs). Study group (30 pairs); control group (30 pairs)	Dementia: moderate–severe	Quantitative. Randomised controlled trial. Pre-/post-tests. Follow-up (12-18 months)	Carergiver Support Programme	6 months	Standard outcome measures: burden; depression; anxiety; quality of life; health; impact of caring	Canada
41	Pritchard and Dewing (2001)	Interviews: clients (5); carers (5); others(23). Questionnaires: numbers not given	Alzheimer's disease	Mixed. No control group. Post-test	SPECAL (Specialized Early Care of Alzheimer's)	Not given	Development of project/services; quality of services/approach; factors for future development	UK
52	Millan-Calenti <i>et al.</i> (2000)	Carers (14)	Alzheimer's disease	Quantitative. No control. Pre-/post-tests. Follow-up (12 months)	Support Programme	Not given	Standard outcome measures: physical and mental health; social life; support; burden; anxiety	Spain
119	Chu <i>et al.</i> (2000)	Client–carer pairs (75 pairs). Study group (37 pairs); control group (38 pairs)	Early-stage Alzheimer's disease	Quantitative. Control group. Pre-/post-tests	Early Home Care Programme	18 months	Standard outcome measures: burden; disturbing behaviours; depression. Records of service use	Canada

## Services to Support Carers of People with Mental Health Problems

**Table 15 Multidimensional approaches to caring interventions (continued)**

Study number	Author(s)	Sample	Care recipient group	Research methods	Intervention	Duration of intervention	Outcomes	Setting
127	Benson <i>et al.</i> (1996)	Families (579); support staff	Mental illness	Mixed. No control. Pre-/follow-up tests (at 6 months)	Massachusetts Family Support Demonstration Project	Varied	Standard outcome measures: service utilisation; satisfaction; family stress; family burden; attitudes toward professionals	USA
169	Carpentier <i>et al.</i> (1992)	Patients and families(37). Study group (15); control group (22)	Schizophrenia (18–30 years)	Mixed. Control group. Post-tests	Programme providing comprehensive support services	One year minimum	Standard outcome measures: burden; psychological distress; behavioural problems; types of professionals seen; number of services received; need for services	Canada
171	Yordi <i>et al.</i> (1997)	Carers (5,254). Study/Model B (MADD expanded services/high resources) (2707). Control/Model A (MADD low resources) (2547)	Dementia	Quantitative. Randomised control trial. Baseline and five further assessments	MADD (Medicare Alzheimer Disease Demonstration). Two case management models: one high resource, and one low resource	36 months	Standard outcome measures: functional status; behavioural problems; hours per week caring; activities undertaken; informal help; formal help; unmet needs	USA

## Services to Support Carers of People with Mental Health Problems

**Table 15 Multidimensional approaches to caring interventions (continued)**

Study number	Author(s)	Sample	Care recipient group	Research methods	Intervention	Duration of intervention	Outcomes	Setting
176	Fisher and Savin-Baden (2001)	Patients (5); carers/relatives (1); professionals (7)	Schizophrenia or related disorder (16–25 years)	Qualitative. No control. No pre-participation measures. Interviews with all key stakeholder groups	TIME (occupational therapy programme)	6 months	Evaluation of the TIME programme	UK
203	Drummond <i>et al.</i> (1991)	Carers (60). Study group (30); control group (30)	Dementia (moderate–severe)	Quantitative. Randomised controlled trial. Pre-/post-tests	Caregiver Support Programme (CSP)	6 months	Standard outcome measures: depression; anxiety; quality of life	Canada
208	Fox <i>et al.</i> (2000)	Clients (8095). Study group (4151); control group (usual care) (3944)	Dementia	Quantitative. Randomised controlled trial. Baseline and five further assessments	MADD (Medicare Alzheimer Disease Demonstration). Two case management models: one high resource, and one low resource	36 months	Standard outcome measures: carer burden; depression	USA
238	Newcomer <i>et al.</i> (1999a)	Clients (5307). Study group (2731); control group (usual care) (2576)	Dementia	Quantitative. Randomised controlled trial. Baseline and five further assessments	MADD (Medicare Alzheimer Disease Demonstration). Two case management models: one high resource, and one low resource	36 months	Standard outcome measures: carer burden; depression	USA

## Services to Support Carers of People with Mental Health Problems

**Table 15 Multidimensional approaches to caring interventions (continued)**

Study number	Author(s)	Sample	Care recipient group	Research methods	Intervention	Duration of intervention	Outcomes	Setting
239	Newbronner <i>et al.</i> (1999b)	Clients (8,095). Study group (4151); control group (usual care) (3944)	Dementia	Quantitative. Randomised controlled trial. Baseline and five further assessments	MADD (Medicare Alzheimer Disease Demonstration). Two case management models: one high resource, and one low resource	36 months	Standard outcome measures: carer burden; depression. Medicare claims records	USA
260	Spoor (1988)	Carers of EMI (size N/A)	Elderly mentally ill (EMI)	Option appraisal exercise	Current care. Comparator: low/medium/high frequency service provision	12 months		UK
267	Weinberger <i>et al.</i> (1993b)	Carers (264). Study group (193); control group (71)	Progressive memory disorders	Quantitative. Randomised controlled trial. Pre-/post-tests	Individualised service plans (designed to enhance compliance)	6 months	Standard outcome measures: health services utilisation and expenditures	USA
268	Wenger <i>et al.</i> (2000)	Patients and carers (50 pairs). Study group (27 pairs); control group (23 pairs)	Dementia	Mixed. Matched controls. Pre-/post-tests	Early intervention, including specialist input by 'Dementia Care Specialist'	15 months	Standard outcome measures: support network; loneliness and isolation; difficulties; satisfactions; managing/coping; psychological distress; anxiety; depression	UK

## Services to Support Carers of People with Mental Health Problems

**Table 16 Miscellaneous (N = 8)**

Study number	Author(s)	Sample	Care recipient group	Research methods	Intervention	Duration of intervention	Outcomes	Setting
27	Quayhagen <i>et al.</i> (2000)	Carer–patient dyads (103). Cognitive stimulation group (21); dyadic counselling group (29); dual seminar group (22); early day care group (16); control group (15)	Dementia: mild–moderate	Quantitative. Control group. Pre-/post-tests	One of four treatment programmes: cognitive stimulation; dyadic counseling; dual supportive seminar; early-stage day care	8 weeks	Standard outcome measures: marital interaction, emotional status, physical health, stress, coping and social support. Programme evaluation questionnaire	USA
28	Cohen <i>et al.</i> (1998)	Carers (7)	Dementia	Mixed. No control group. Pre-/post-tests	Network therapy	Not clear	Standard outcome measures: social support; burden	Canada
163	Simpson (1997)	Carers (20); Community Mental Health Team professionals	Dementia	Mixed. No control. Post-tests	Carer-held record documentation	6 months	Evaluation interviews (questionnaire; verbatim comments): assess carers' satisfaction with system, evaluate use of document by carers and multidisciplinary team members. Assess carers' roles as partners with professionals	UK

## Services to Support Carers of People with Mental Health Problems

**Table 16 Miscellaneous (continued)**

Study number	Author(s)	Sample	Care recipient group	Research methods	Intervention	Duration of intervention	Outcomes	Setting
166	Perodeau <i>et al.</i> (2001)	Carers (194). Drug users (61). Non-users (133)	Dementia	Secondary data analysis of earlier study. Quantitative. Control group. Post-test only	Psychotropic drug use	Varied	Standard outcome measures: psychotropic drug-use; psychological distress; dysfunctional behaviours; conflicts in interpersonal relationships; coping strategies; social support; health status	Canada
167	Winslow (1998)	Carer (1); service providers (2)	Alzheimer's disease	Qualitative. Case study approach. Post-test only	Formal community support services	18 months	In-depth interviews; observations: carer's experiences of services	USA
177	Aimonino <i>et al.</i> (2001)	Patients (82). HHS (41). GMW (41). Carers (numbers not given)	Dementia: advanced	Quantitative. No control. Tests at admission and discharge	Home Hospitalisation Service (HHS). Comparator: patients in a general medical ward (GMW)	Varied	Standard outcome measures: stress	Italy
232	Knapp <i>et al.</i> (1998)	Patients (189) DLP (92); control (97)	Severe mental illness	Quantitative. Randomised controlled trial. Pre-/post-tests. Follow-up (4 years)	Daily Living Programme (DLP) for 45 months. Comparators: DLP (20 months) plus standard care (25 months); standard care (45 months)	Varied	Standard outcome measures: social. Patients' and relatives' satisfaction	UK

***Services to Support Carers of People with  
Mental Health Problems***

**Table 16 Miscellaneous (continued)**

<b>Study number</b>	<b>Author(s)</b>	<b>Sample</b>	<b>Care recipient group</b>	<b>Research methods</b>	<b>Intervention</b>	<b>Duration of intervention</b>	<b>Outcomes</b>	<b>Setting</b>
250	Rudolph <i>et al.</i> (1998)	Patients (76); carers (32)	Mental retardation	Quantitative. Longitudinal study with hypothetical controls	Behavioural support and crisis response	Varied	Care-provider and case manager satisfaction levels	USA



## ***Appendix 5***

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Interventions to support carers of patients with  
mental health problems: summary of findings  
from the economic literature

## Services to Support Carers of People with Mental Health Problems

### Summary of findings from the economic literature

Study number	Author(s)	Intervention category group	Sample	Care recipient group	Research methods	Intervention	Duration of intervention	Outcomes	Setting (currency)
196	Brodaty (1991)	Education – training	Patient–carer pairs (96 pairs). Immediate carer training (33). 6-month delayed carer training (32). Patient memory retraining/no training for carers (31)	Dementia (mild to moderate)	Quantitative. Control group. Pre-/post-tests. Follow-up (to 3 years)	10-day residential care-giver training programme; 10-day memory retraining programme for patients	10 days	Standard outcome measures: carer stress; neuroticism; satisfaction impact of training on nursing home admission and/or survival to death	Australia hospital PU (\$A, US\$)
200	Creed (1997)	Breaks from caring – ADC	89 inpatients (52 carers); 90 day patients (51 carers)	Acute psychiatric illness	Quantitative. Randomised control trial. Pre-tests; regular follow-up (up to 12 months)	Day hospital vs. routine inpatient care for persons with acute psychiatric illness	Varied	Standard outcome measures: carer distress. Cost - effectiveness	UK hospital (£)
201	Donaldson (1989)	Breaks from caring – mixed respite	EMI patients (105); 35 intervention (24 carers); 70 controls (29 carers)	Elderly mentally infirm (EMI)	Quantitative. Case series with matched controls. Pre-/post-tests	Family support unit (co-ordinated and flexible community care)	Varied	Costs, benefits and effects of providing care for carers	UK (Scotland) community (£)
203	Drummond (1991)	Multidimensional	Carers (60). Study group (30); control group (30)	Dementia (moderate – severe)	Quantitative. Randomised controlled trial. Pre-/post-tests	Caregiver Support Programme (CSP)	6 months	Standard outcome measures: depression; anxiety; quality of life	Canada community (CAN\$)

## Services to Support Carers of People with Mental Health Problems

### Summary of findings from the economic literature (continued)

Study number	Author(s)	Intervention category group	Sample	Care recipient group	Research methods	Intervention	Duration of intervention	Outcomes	Setting (currency)
208	Fox (2000)	Multidimensional	Clients (8095) Study group (4151); control group (usual care) (3944)	Dementia	Quantitative. Randomised controlled trial. Baseline and five further assessments	MADD (Medicare Alzheimer Disease Demonstration). Two case management models: one high resource, and one low resource	36 months	Standard outcome measures; carer burden; depression	US community (US\$)
208	Fox (2000)	Multidimensional	Clients (8095) Study group (4151); control group (usual care) (3944)	Dementia	Quantitative. Randomised controlled trial. Baseline and five further assessments	MADD (Medicare Alzheimer Disease Demonstration). Two case management models: one high resource, and one low resource	36 months	Standard outcome measures; carer burden; depression	US community (US\$)
232	Knapp (1998)	Miscellaneous	Patients (189). DLP (92); control (97)	Severe mental illness	Quantitative. Randomised controlled trial. Pre-/post-tests. Follow-up (4 years)	Daily Living Programme (DLP) for 45 months. Comparators: DLP (20 months) plus standard care (25 months); standard care (45 months)	Varied	Standard outcome measures: social. Patients' and relatives' satisfaction	UK community (£)
242	Payton (1995)	Technology	Carers (96). Study group (47); control group (49)	Alzheimer's disease	Quantitative. Randomised controlled trial. Pre-/post-tests	ComputerLink (specialised computer network)	12 months	Institutionalisation rate	US community (US\$)

## ***Services to Support Carers of People with Mental Health Problems***

### **Summary of findings from the economic literature (continued)**

<b>Study number</b>	<b>Author(s)</b>	<b>Intervention category group</b>	<b>Sample</b>	<b>Care recipient group</b>	<b>Research methods</b>	<b>Intervention</b>	<b>Duration of intervention</b>	<b>Outcomes</b>	<b>Setting (currency)</b>
250	Rudolph (1998)	Miscellaneous	Patients (76). Carers (32)	Mental retardation	Quantitative. Longitudinal study with hypothetical controls	Behavioural support and crisis response	Varied	Care provider and case manager satisfaction levels	US community (US\$)
260	Spoor (1988)	Multidimensional	Carers of EMI (size N/A)	Elderly mentally ill (EMI)	Option appraisal exercise	Current care. Comparator: low/medium/high frequency service provision	12 months		UK domiciliary (£)
261	Tarrier (1991)	Family	Carers (73); High EE study group (25); High EE control group (29); Low EE control group (19)	Schizophrenia	Quantitative. Control group. Pre-/post-tests	Nine month family intervention. Comparator: short educational programme or routine care	9 months	Relapse rate in patients	UK community (£)
263	Van Minnen (1997)	Family	Patients (50); Outreach treatment (25); Hospital care/control (25)	Serious mental illness	Quantitative. Randomised controlled trial. Pre-/post-tests	Outreach treatment. Comparator: hospital care	28 weeks	Standard outcome measures: family burden. Hospital admissions	Netherlands mixed (US\$)

## ***Services to Support Carers of People with Mental Health Problems***

### **Summary of findings from the economic literature (continued)**

<b>Study number</b>	<b>Author(s)</b>	<b>Intervention category group</b>	<b>Sample</b>	<b>Care recipient group</b>	<b>Research methods</b>	<b>Intervention</b>	<b>Duration of intervention</b>	<b>Outcomes</b>	<b>Setting (currency)</b>
268	Wenger (2000)	Multidimensional	Patients and carers (50 pairs). Study group (27 pairs); control group (23 pairs)	Dementia	Mixed. Matched controls. Pre-/post-tests	Early intervention, including specialist input by 'Dementia Care Specialist'	15 months	Standard outcome measures: support network; loneliness and isolation; difficulties; satisfactions; managing/coping; psychological distress; anxiety; depression	UK community (£)
274	Cardin (1985)	Family	Patients (36). Family management (18). Individual management (18)	Schizophrenia	Quantitative. Randomised controlled trial. Pre-/post-tests	Family management. Comparator: individual supportive management	24 months	Standard outcome measures: family burden; carer satisfaction	US community (US\$)

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