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Executive Summary

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.

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.

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.

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.

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.
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
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
implementation of Standard 6 and Standard 7 in the NSFs for Mental Health and Older People respectively. 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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1 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.
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.
All citations were downloaded or entered by hand into an Endnote® 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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2 Endnote is a reference database that stores, manages and searches for bibliographic references.
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- SIGLE (2001)
- Social Science Citation Index (SSCI) (1985–2001)
- Sociological Abstracts 1986–2001/09

**Internet resources**

- Caredata
  
  [http://www.elsc.org.uk/uc.htm](http://www.elsc.org.uk/uc.htm)

- Database of Abstracts of Reviews of Effectiveness (DARE)
  
  [http://www.york.ac.uk/inst/crd](http://www.york.ac.uk/inst/crd)

- Health Technology Assessment Database (HTA)
  
  [http://www.york.ac.uk/inst/crd](http://www.york.ac.uk/inst/crd)

- NHS Economic Evaluations Database (NHS EED)
  
  [http://www.york.ac.uk/inst/crd](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.
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)
- Alzheimer’s 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
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.
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
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>
<thead>
<tr>
<th>Bibliographic source</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Electronic and specialist bibliographic databases and registers</td>
<td>3755</td>
<td>97</td>
</tr>
<tr>
<td>Hand searches</td>
<td>15</td>
<td>0.4</td>
</tr>
<tr>
<td>Reference checking</td>
<td>93</td>
<td>2.4</td>
</tr>
<tr>
<td>Internet searches</td>
<td>0</td>
<td>0.2</td>
</tr>
<tr>
<td>Personal contacts</td>
<td>4</td>
<td>0.2</td>
</tr>
</tbody>
</table>

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.
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)

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

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

<table>
<thead>
<tr>
<th></th>
<th>Alzheimer’s disease/ dementia</th>
<th>Schizophrenia</th>
<th>Other serious mental illness</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No</td>
<td>%</td>
<td>No</td>
</tr>
<tr>
<td>USA</td>
<td>90</td>
<td>44</td>
<td>8</td>
</tr>
<tr>
<td>UK</td>
<td>18</td>
<td>9</td>
<td>14</td>
</tr>
<tr>
<td>Canada</td>
<td>13</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>Australia</td>
<td>9</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Rest of Europe</td>
<td>*10</td>
<td>5</td>
<td>–</td>
</tr>
<tr>
<td>Rest of world</td>
<td>†2</td>
<td>1</td>
<td>††4</td>
</tr>
<tr>
<td>Total</td>
<td>142</td>
<td>70</td>
<td>31</td>
</tr>
</tbody>
</table>

* 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
Services to Support Carers of People with Mental Health Problems

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)

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

* 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)

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

* 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)

<table>
<thead>
<tr>
<th>Type of Research</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quantitative methods</td>
<td></td>
<td></td>
</tr>
<tr>
<td>RCTs</td>
<td>53</td>
<td>33</td>
</tr>
<tr>
<td>before-and-after studies (uncontrolled)</td>
<td>51</td>
<td>31</td>
</tr>
<tr>
<td>non-randomised controlled trials</td>
<td>33</td>
<td>20</td>
</tr>
<tr>
<td>post-intervention measures</td>
<td>25</td>
<td>16</td>
</tr>
<tr>
<td>Mixed or multiple methods</td>
<td>22</td>
<td>11</td>
</tr>
<tr>
<td>Qualitative methods</td>
<td>13</td>
<td>6</td>
</tr>
<tr>
<td>Other*</td>
<td>7</td>
<td>3</td>
</tr>
</tbody>
</table>

* 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.
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, 123)
- author(s)
- study sample
- care recipient group
- research methods
- intervention type
- duration of intervention
- outcomes
- setting.
Services to Support Carers of People with Mental Health Problems

4.1 Breaks from caring (N = 36)

Day care services (N = 12)

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

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\(^{199}\) 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\(^{35}\) 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\(^{181}\) to 324\(^{78}\). 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\(^{121}\), the age range of carers spanned 27–88 years. One study\(^{230}\) 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\(^{230}\), 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\(^{230}\) compared adult day care services based on a medical model with services based on a social model. Three studies\(^{35, 78, 121}\) 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
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\textsuperscript{118, 181} and that it is the benefits to the patient that encourage carers to use these services\textsuperscript{121}. 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\textsuperscript{37, 156} are not reflected in the results of pre- and post-test outcome measures where little or no improvement has been found\textsuperscript{35, 156}. These studies contradict those that have found some evidence of long-term effects on carers, including one\textsuperscript{200} that reported reduced levels of burden and another\textsuperscript{78} 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\textsuperscript{34} 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\textsuperscript{200}. 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\textsuperscript{200} 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.
In-home respite care (N = 4)

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

Interventions: The interventions varied. The UK study\(^{117}\) 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\(^{186}\) 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\(^{77}\) 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\(^{186}\) to 80\(^{214}\).

Participants: One study\(^{77}\) 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\(^{117}\) also consisted of more women than men. Care recipients in all four studies suffered from dementia. In the Swedish study\(^{77}\), 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\(^{77}\).
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and some improvement in perceived carer burden and coping 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 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 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)

Study identification code numbers: 4, 6, 50, 182, 189

(see Table 3 in Appendix 4)

Care recipient group: AD/dementia (3), schizophrenia (0), other serious mental illness (2)

Setting: USA (3), UK (1), Canada (1)

Main measures of effectiveness: 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 was different in that it was a night nursing service for elderly people suffering from dementia. One US intervention studied 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 to 70.

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 focused on people with mental illnesses; in one case patients were male veterans. The respite camp study 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.
Services to Support Carers of People with Mental Health Problems

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 and an increase in positive feelings for some carers. It is the negative aspects of institutional respite that are perhaps of more interest; for example, one study reported worse relationships between some carers and care recipients on return and another 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, while the other reported positive evaluations from carers and staff of annual respite camps.

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.
Mixed respite care services (N = 15)

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

Interventions: Six of the studies looked at large-scale respite demonstration programmes in the USA. Two articles 85, 154 reported on the respite programme established in the state of Maryland for carers of people with Alzheimer’s disease. A further two articles 7, 64 reported on the Michigan Model Projects Specialised Respite Care Programme, and the remaining two papers 10, 229 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 39, 93, 153, 157 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’ 85, 154. Some 632 carers, distributed in either a treatment group or a control group, took part in the Philadelphia programme 10, 229.

Participants: Carers participated in all the studies, but not all of them used the respite services under investigation. In one case 9 the sample consisted of only female carers (wives or daughters). In one UK study 157, 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 39 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 9 compared in-home respite services with adult day care services. Others made comparisons between users and non-users of respite care.
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 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, 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, increased carer morale, and reductions in carer stress. 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 reporting that respite users were more likely to maintain their relative in the community and another 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 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 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 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
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 \(^{39, 86, 157, 201, 234}\) used mainly qualitative methods. One piece of research \(^{39}\) 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 \(^{157}\), 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 \(^{86}\), north-east England \(^{201}\) and Kent \(^{234}\).

**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 \(^{81}\) 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)**

<table>
<thead>
<tr>
<th>Study identification code numbers</th>
<th>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</th>
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<tbody>
<tr>
<td>Care recipient group</td>
<td>AD and dementia (17), schizophrenia (5), other serious mental illness (7)</td>
</tr>
<tr>
<td>Setting</td>
<td>USA (17), UK (8), Italy (2), Canada (1), Ireland (1)</td>
</tr>
<tr>
<td>Main measures of effectiveness</td>
<td>Standard outcome measures (17), programme evaluation/satisfaction surveys (9)</td>
</tr>
</tbody>
</table>

**Interventions:** Of the 29 articles retrieved, two \(^{102, 272}\) 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
family members; and yet others by both professionals and carers. Two studies focused on the roles of community psychiatric nurses in the provision of education and information to carers and relatives, and another on the role of occupational therapists.

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 focused specifically on legal and financial matters. There was a pilot study 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. 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 and 424 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 to carers in their 80s and even 90 in one case. One educational intervention was for patients in the early stages of Alzheimer’s disease; another was for people with Huntington’s disease. One study 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. Another study 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. However, there is less evidence to support the claim that increasing knowledge leads to reductions in stress or burden among carers. Although one study found decreases in
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 168 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 120, 145.

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 49, 102, 159, 162, 164, 272, 286, 287 reporting on seven different interventions. Two studies examined educational support for carers of people with dementia 159, 162, 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 102, 272, compared three different methods to deliver educational interventions (see above). Two unrelated studies 159, 164 looked at the role and impact of community psychiatric nurses in providing education and support to relatives. One study 159 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)

Study identification code numbers (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

Care recipient group AD and dementia (21), schizophrenia (0), other serious mental illnesses (0)

Setting USA (12), Australia (5), Canada (2), UK (2)

Main measures of effectiveness Standard outcomes measures (18), programme evaluation/satisfaction surveys (4)

Interventions: There were 21 relevant articles. Of these, four papers 96, 144, 196, 273 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 \(^{129,188}\) featured the same intervention, a training programme designed to improve carers’ communication skills with the person supported. Other interventions included a stress management programme \(^{59}\), a relaxation training programme \(^{17}\) and treatment to reduce sleep problems \(^{126}\). Programmes tended to be short, the longest lasting for 12 weeks \(^{73}\). 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 \(^{188}\).

Some eight \(^{71,90,135,147,151,179,180,184}\) of the training interventions could be described as ‘dual target’ (Silliman \textit{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 \(^{180}\) 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 \(^{96,144,196,273}\), 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 \(^{90,135,151,179}\) with 65 or more carer–patient dyads.

**Participants:** Training interventions were often aimed at main and/or spouse carers. One stress management programme \(^{59}\) 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 \(^{129,188}\) or mild to moderate dementia \(^{196,273}\). Some interventions involved carer–patient dyads. Exceptionally, data were also collected from day care staff in one study \(^{188}\).

**Research methods:** The methods adopted in the majority of studies were quantitative. One action research study \(^{180}\) 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 \(^{144}\). There were a number of comparative studies. For example, one study \(^{73}\) compared the effects of two different training interventions: a behaviour management programme and a social skills programme. Another \(^{66}\) 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
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, delay and reductions in institutionalisation, improved quality of life, and reduced carer depression. However, some researchers 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 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, relaxation techniques and stress management, 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 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. One evaluated a structured stress management programme followed by seven carers of people with dementia. The second study 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, 127). All
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)

<table>
<thead>
<tr>
<th>Study identification code numbers</th>
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<td>Care recipient group</td>
<td>AD and dementia (11), schizophrenia (8), other serious mental illness (4)</td>
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<tr>
<td>Setting</td>
<td>USA (14), Australia (3), Japan (2), UK (1), Germany (1), Netherlands (1), China (1)</td>
</tr>
<tr>
<td>Main measures of effectiveness</td>
<td>Standard outcome measures (18), programme evaluation/satisfaction surveys (9)</td>
</tr>
</tbody>
</table>

Interventions: The literature search produced 24 relevant articles. There
were three separate occurrences of two papers 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 was specifically for spouses (of people with serious mental illness),
and another was directed at male carers (of patients with Alzheimer’s
disease). A third 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. On the other hand, three studies
had over 220 participants. The completed sample in a fourth study, 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, spouses, female carers, and male

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, two were for people with
bipolar disorder and one was for elderly people with recurrent major
depression. In some cases, participants were carer–patient dyads or families.
The one UK study 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 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. There were some comparison studies; for example, one study compared two models of brief psychosocial education.

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 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 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.

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. Only one study 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.

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 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, 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 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)

**Study identification code numbers**
(see Table 8 in Appendix 4)


**Care recipient group**
AD and dementia (1), schizophrenia (13), other serious mental illness (6)

**Setting**
UK (13), USA (4), Netherlands (1), China (1), Malaysia (1)

**Main measures of effectiveness**
Standard outcomes measures (16), programme evaluation/satisfaction surveys (1)

**Interventions:** Of the 20 articles, there were four instances of two papers 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 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 evaluated a newly developed comprehensive
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 \(^{112; 116; 172}\) had study samples of 31 of fewer. At the other extreme, there was one study \(^{60}\) with 224 participants.

**Participants:** As with other types of interventions, carer participants were mainly women. One US study \(^{60}\) of family-based therapy was aimed at white American and Cuban American primary carers. Similarly, a UK study \(^{271}\) 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 \(^{92}\), 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 \(^{112; 172}\) were qualitative, and one \(^{92}\) 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 \(^{60}\), 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 \(^{60}\) 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 \(^{101; 108; 109; 261; 289}\), although one study found no effect on ‘expressed emotion’ (EE) or relapse \(^{99}\).

Other aspects of the effectiveness of family therapy have also been identified by these studies, including: improvements in patient behaviour \(^{116; 165}\), improvements in family relationships \(^{110; 172; 275}\) and reductions in family burden \(^{92; 103; 108; 165}\).

Only two studies have considered the differences between services or components of services in relation to potential effectiveness. One \(^{165}\) 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 \(^{112}\) 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.
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 \(^{261; 263; 274}\) included an economic evaluation of family interventions. Two studies \(^{261; 274}\) targeted support at families of patients with schizophrenia and one \(^{263}\) addressed patients with severe mental illness and concurrent mild mental retardation. All studies enrolled fewer than 75 patients. In the US study \(^{274}\), 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 \(^{261}\), 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 \(^{263}\). 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 \(^{261}\) found the intervention to be cost-saving, mainly due to differences in the between-group rate of hospitalisation. The US study \(^{274}\) 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 \(^{263}\) 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 \(^{101; 103; 109; 110; 275}\) were published in 1990 or earlier. These five were all studies of family therapy programmes. For example, two articles \(^{101; 109}\) 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 \(^{110; 275}\) 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 \(^{112; 137}\) 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...
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 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 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 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)**

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

**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. The two Canadian papers discussed the same support group; so, too, did two US articles.

Support groups in some studies set in the USA were affiliated with specific organisations, such as the Alzheimer’s Association and the National Alliance for the Mentally Ill. 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
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 $^{161}$, and the largest was 348 $^{3}$. 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 $^{11/12}$ 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 $^{8}$ was of people with schizophrenia and bipolar disorders. Support group leaders were included in one study $^{3}$.

**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 $^{51}$.

**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 $^{13}$ 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 $^{89; 91; 123; 161}$.

Some studies have addressed the question of who might benefit from support groups. Reported findings suggest that carers in most distress $^{51}$ and carers most dissatisfied with their role $^{91}$ 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 $^{8}$. 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 $^{173}$. It might be argued that this conclusion is relevant to all forms of support groups for carers of people with mental health problems.
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. 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 that was based on alternative models of carer stress using ‘affiliated-individuation’ theories reported more positive outcomes for carers 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)

<table>
<thead>
<tr>
<th>Study identification code numbers</th>
<th>45, 46, 47, 67, 74, 95, 115, 207, 249</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Care recipient group</strong></td>
<td>AD and dementia (7), schizophrenia (1), other serious mental illness (1)</td>
</tr>
<tr>
<td><strong>Setting</strong></td>
<td>USA (6), UK (1), Australia (1), Canada (1)</td>
</tr>
<tr>
<td><strong>Main measures of effectiveness</strong></td>
<td>Standard outcomes measures (9), programme evaluation/satisfaction surveys (1)</td>
</tr>
</tbody>
</table>

**Interventions:** Of the nine articles focusing on counselling interventions for carers, three papers were about the same counselling programme implemented in the USA. This particular programme included individual and
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 had fewer than 45 participants. The study sample in the largest inquiry totalled 206 carers, divided equally between the treatment and control group.

Participants: One of the interventions 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, 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 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 compared with control groups. The effect of counselling on psychiatric symptoms among carers is mixed. Researchers report no effect on psychiatric symptoms or psychological distress respectively. Others report reduced depression among carers using counselling services, and yet others 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, particularly during the early and middle stages of dementia. 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.

The evidence with regard to counselling services is patchy and incomplete. Although there is no evidence to suggest counselling has negative
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 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 \((N = 16)\)

<table>
<thead>
<tr>
<th>Study identification code numbers</th>
<th>25, 26, 38, 62, 63, 94, 97, 98, 133, 134, 136, 152, 170, 242, 284, 288</th>
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<tr>
<td>Care recipient group</td>
<td>AD and dementia (16), schizophrenia (0), other serious mental illness (0)</td>
</tr>
<tr>
<td>Setting</td>
<td>USA (16)</td>
</tr>
<tr>
<td>Main measures of effectiveness</td>
<td>Standard outcomes measures (12), programme evaluation/satisfaction surveys (2)</td>
</tr>
</tbody>
</table>

**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 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 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; whether the use of a computer network fostered collaboration among carers, and between carers and health care professionals; and attitudes towards, and usage of, ComputerLink. The first ComputerLink project was designed to reach people with AIDS, and one article compared the use patterns of people with AIDS with those of carers of people with Alzheimer’s disease.

The one remaining computer-related study 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 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 concentrated on a comparison of the two different programme components and the impact of both components over time, while the other looked at the effect of Care-Line on carers’ natural supports.

Sample sizes: The smallest sample size comprised four women in a study looking at the efficacy of short-term telephone counselling, and the largest was 104. 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 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 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,
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 \(^{26; 133; 134}\) as well as offering carers access to information \(^{170}\). Evidence regarding the effectiveness of these interventions is more limited. While one study \(^{288}\) 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 \(^{94}\).

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 \(^{63}\); reduction in stress and burden \(^{284}\); and increases in life satisfaction and use of social support \(^{63}\). Telephone help-lines and networks appeared to have a positive impact in relation to information and social support \(^{25; 38; 62}\), 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) \(^{62}\).

**Economic aspects:** One study \(^{242}\) addressed the cost implications of ComputerLink, details of which are given above. The authors found a one percent 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.
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)

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

Interventions: Two 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 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 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 comprised 38 patient–carer pairs; the sample size in the other UK study was unclear. The Netherlands’ study 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.

Research methods: All the studies used quantitative methods, control groups and pre- and post-tests, with the exception of one 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)

<table>
<thead>
<tr>
<th>Study identification code numbers</th>
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<tbody>
<tr>
<td>(see Table 13 in Appendix 4)</td>
<td></td>
</tr>
<tr>
<td>Care recipient group</td>
<td>AD and dementia (3), schizophrenia (0), other serious mental illness (0)</td>
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<tr>
<td>Setting</td>
<td>USA (3)</td>
</tr>
<tr>
<td>Main measures of effectiveness</td>
<td>Standard outcomes measures (2)</td>
</tr>
</tbody>
</table>

Interventions: Two of the articles 183, 187 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 178 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 178, compared with 171 carers in another 183. The total number of participants was not given in the third study 187, 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 178 used carer–patient dyads.

Research methods: Two of the studies 178, 183 adopted quantitative methods; just one 183 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 187 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.
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 although the research did not address whether such provision reduced negative aspects of caring for carers. The Occupational Therapy programme 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 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)

Study identification code numbers
(see Table 14 in Appendix 4)

| Study identification code numbers | 138, 190 |

Care recipient group
AD and Dementia (2), schizophrenia (0), other serious mental illness (0)

Setting
UK (1), Australia (1)

Main measures of effectiveness
Standard outcomes measures (2)

Interventions: The UK study 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 similarly investigated the
impact of a memory clinic on the psychosocial health status and burden of

carers of people with cognitive impairment.

Sample sizes: The UK study \(^{190}\) involved 30 patient–carer pairs. There were

50 patient–carer pairs in the Australian research \(^{138}\).

Participants: Both studies gathered data from carers supporting people with
dementia. The Australian study’s \(^{138}\) sample comprised mainly older women. The

UK research \(^{190}\) 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 \(^{138}\), and 18
months in the other \(^{190}\). The UK study \(^{190}\) 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 \(^{190}\) and
psychosocial health-related quality of life \(^{138}\). 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 \(^{196}\) 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)

Study identification code numbers
(see Table 15 in Appendix 4)
29, 41, 52, 119, 127, 169, 171, 176, 203, 208, 238, 239, 260, 267, 268

Care recipient group
AD and dementia (11); schizophrenia (2); other serious mental illness (2)

Setting
USA (6), UK (4), Canada (4), Spain (1)

Main measures of effectiveness
Standard outcomes measures (12), programme evaluation/satisfaction surveys (1)

Interventions: Some four papers \[171; 208; 238; 239\] 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, coordinated formal assistance and monitored the quality of services provided by demonstration service providers. Another piece of research \[127\] 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 \[29; 203\]. 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 \[41; 176; 260; 268\] are discussed in more detail below. Three provided early intervention, in two cases \[41; 268\] for people with Alzheimer's disease or other form of dementia, and in the third case \[176\] for young people between the ages of 16 and 25 experiencing psychosis.

Sample sizes: The study samples in three studies \[41; 52; 176\] numbered 37 or less. At the other extreme, the total demonstration sample in MADD \[171; 208; 238; 239\] 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 \[176\], professionals (including consultant psychiatrists and occupational therapists). Some interventions focused on primary carers. Samples often comprised female carers rather than male carers.
Two interventions were for younger people with schizophrenia: in one case, 18–30-year-olds and in the other 16–25-year-olds.

**Research methods:** The majority of the studies used quantitative, repeated measures. Four used mixed methods, and just one 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. One UK study 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 of multidimensional approaches reported an economic analysis. All four studies addressed elderly patients with dementia, and one study included elderly individuals with any type of psychiatric disorder.

All but one of the studies included some type of break from caring in the package of care. Three studies offered in-home respite. All studies except one included some form of educational intervention, and support groups or changes to the physical environment 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 reported that carers appeared to have substituted the intervention services for those already used. The other study, 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 found that low-frequency packages of care were cost-effective relative to usual care, while the Canadian trial reported a cost-per-QALY that compared favourably with other health care interventions.

**UK studies:** One study 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 evaluated SPECAL, a dementia care service.
Services to Support Carers of People with Mental Health Problems

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 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. 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)

<table>
<thead>
<tr>
<th>Study identification code numbers</th>
<th>27, 28, 163, 166, 167, 177, 232, 250</th>
</tr>
</thead>
<tbody>
<tr>
<td>Care recipient group</td>
<td>AD and dementia (6), schizophrenia (0), other serious mental illness (2)</td>
</tr>
<tr>
<td>Setting</td>
<td>USA (3), Canada (2), UK (2), Italy (1)</td>
</tr>
<tr>
<td>Main measures of effectiveness</td>
<td>Standard outcomes measures (5), programme evaluation/satisfaction surveys (4)</td>
</tr>
</tbody>
</table>

Interventions: One of the US studies 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, 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 comprised a two-year demonstration project in Minnesota, USA, providing outreach services to the patient’s home and offering crisis placement services in a specialised unit.

A study 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 compared carers who
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 163 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 232, discussed in more detail below, evaluated a UK-based assertive outreach programme, the Daily Living Programme (DLP).

The study from Italy 177 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 28; 167 had very small samples, of seven or fewer. Some 103 carer–patient pairs took part in the study 27 comparing four different treatment programmes. Some 194 carers participated in the largest study 166, which examined psychotropic drug use research 166.

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

Research methods: Four studies 27; 177; 232; 250 were quantitative, two 28; 163 used a mixed-methods approach, and there was one 167 qualitative study. One study 166 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 27 to carer empowerment 163:167. It is the innovative approach that these interventions represent that is of most interest, particularly the work 163 on care plan documentation packs and Network Therapy 28. Although the former 163 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 28 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 232; 250 in this category addressed the cost-effectiveness of assertive outreach for patients. One study 232 evaluated a UK-
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 that addressed cost issues was the two-year demonstration project 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 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)

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

Interventions: Types of interventions included in the economic studies included three family intervention studies 274; 261; 263 and breaks from caring, comprising one study of day care services 200 and one of mixed respite services 201. Educational strategies 196 and technological interventions 242 were addressed by one study each. Four studies were of multidimensional interventions and all focused on patients with dementia, although one 260 had a
wider scope, examining elderly patients with any type of psychiatric disorder. A Canadian study \textsuperscript{203} 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 \textsuperscript{208} 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 \textsuperscript{260} and a psychosocial intervention by a dementia specialist, including the provision of information and support \textsuperscript{268}. Two studies were classified under the ‘Miscellaneous’ category. Both reported on assertive outreach programmes for persons with severe mental illness \textsuperscript{232} or mental retardation \textsuperscript{250}, but one of the studies \textsuperscript{232} 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 \textsuperscript{196}.

**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 \textsuperscript{274} and the largest study included an assessment of over 5000 patients \textsuperscript{208}. 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 \textsuperscript{203} to 73 \textsuperscript{261}. One study was an option appraisal exercise and enrolled no actual patients or carers \textsuperscript{260}.

**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) \textsuperscript{201}. 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 \textsuperscript{200}. 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 \textsuperscript{255}. Two studies involved people with a range of diagnoses. One study \textsuperscript{232} included people with schizophrenia, mania, neurosis and depression, and the other \textsuperscript{263} 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.
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. Mean carer age was reported only by the three studies of elderly patients and ranged from 65 to 68; five studies reported the proportion of spouse carers, two reported carer social class and three reported the proportion of female carers, which ranged from 54 per cent to 72 per cent.

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

The duration of studies (including follow up) ranged from 6 months to 4 years. 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) and another study included measures of loneliness and isolation, carer coping strategies and an assessment of social network. One study that reported multiple measures presented self-reported measures of unmet carer need for support and another measured carer perception of patient benefit. 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. Only one study included a measure of indirect benefits (patient earnings). The impact of changes in process was also evaluated. Delaying the delivery of an intervention was reported by one study and of switching patients from intervention to control care by another. Differences in the care setting were explored by three studies and differences related to the type of professional delivering support by another. A family-focused intervention was compared with a patient-focused intervention by one study.

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 and the other reported no measure of benefit for the control group.

In terms of cost-effectiveness, five studies reported the intervention to be cost-saving, five studies found the

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intervention to be cost-effective in certain circumstances and two studies found the intervention was not cost-effective. The cos–utility analysis found the intervention compared favourably with other health care interventions in terms of its cost per QALY (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. 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. One study 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. 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. However, the resource use implications for this category of cost were explored by a further two studies. Indirect costs were measured by two studies; in one of these, changes in productivity were included on the benefit side of the analysis.

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. Another was a case series with matched controls that included a total of 50 carer–patient dyads and the third study also used matched controls in a case series design – this study included over 100 patients, but only 53 carers. 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).
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 and the third was an observational study with concurrent controls. 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. 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. 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).

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
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*
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.
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, generalizability, 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.
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.
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...
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.
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
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
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
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
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 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 specifically on interventions for 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...
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 Satisfactions 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
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
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
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
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

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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

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 #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

Summary table of studies included in the review
### Table 1  Day care services (N = 12)

<table>
<thead>
<tr>
<th>Study number</th>
<th>Author(s)</th>
<th>Sample</th>
<th>Care recipient group</th>
<th>Research methods</th>
<th>Intervention</th>
<th>Duration of intervention</th>
<th>Outcomes</th>
<th>Setting</th>
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<tr>
<td>34</td>
<td>Jarrott et al. (1999)</td>
<td>Carers (261)</td>
<td>Dementia</td>
<td>Quantitative. No control group. Pre-test. Follow-up (3 and 12 months)</td>
<td>Adult Day Service Programme</td>
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<td>35</td>
<td>Wells et al. (1990)</td>
<td>Carers (219): study group (155); wait list/control (64)</td>
<td>Dementia</td>
<td>Quantitative. Control group. Pre-/post-tests</td>
<td>Special Dementia Day Care Programme</td>
<td>Varied</td>
<td>Standard outcome measures: problem checklist; psychological problems; anxiety; depression; quality of life; guilt; grief</td>
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<td>37</td>
<td>Dziegielewski and Ricks (2000)</td>
<td>Carers (26)</td>
<td>Dementia</td>
<td>Quantitative. Postal survey</td>
<td>Adult Day Programme (social model)</td>
<td>Varied</td>
<td>Programme evaluation and satisfaction survey</td>
<td>USA</td>
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<td>78</td>
<td>Zarit et al. (1998)</td>
<td>Carers (324). Short-term (3 months) study group = 121; control group = 203. Long-term study group (12 months) = 73; control group = 120</td>
<td>Dementia</td>
<td>Quantitative. Control group. Pre-/post-tests. Follow up (12 months)</td>
<td>Adult Day Care</td>
<td>Minimum 2 days/week</td>
<td>Standard outcome measures: stress appraisals and well-being</td>
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## Table 1  Day care services (continued)

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<th>Research methods</th>
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<td>Chu (1991)</td>
<td>Patients (9); carers (9)</td>
<td>Dementia</td>
<td>Not clear</td>
<td>Day Care Centre</td>
<td>Not clear</td>
<td>Impact of day care programme on patient and carer</td>
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<td>156</td>
<td>Johnson and Maguire (1989)</td>
<td>Carers (46)</td>
<td>Alzheimer’s disease and related dementia; schizophrenia; depression</td>
<td>Quantitative. No control. Pre-/post-tests. Follow-up (4 months)</td>
<td>Day Away Centre</td>
<td>From 8 to 24 hours per week</td>
<td>Standard outcome measures: stress; patient behaviour</td>
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<td>Adam et al. (2000)</td>
<td>Patient (1)</td>
<td>Alzheimer’s disease (mild to moderate)</td>
<td>Mixed case study. Initial evaluation; follow-up (3 months)</td>
<td>Day Care Centre</td>
<td>13 weeks</td>
<td>Standard outcome measures: carer burden</td>
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<td>200</td>
<td>Creed <em>et al.</em></td>
<td>89 inpatients (52 carers); 90 day patients (51 carers)</td>
<td>Acute psychiatric illness</td>
<td>Quantitative. Randomised controlled trial. Pre-tests; regular follow-up (up to 12 months)</td>
<td>Day hospital vs. routine inpatient care for persons with acute psychiatric illness</td>
<td>Varied</td>
<td>Standard outcome measures: carer distress. Cost-effectiveness</td>
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<td>Leitsch <em>et al.</em></td>
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<td>Quantitative. No control. Pre-tests; follow-up (3 months). Longer-term follow-up (to discharge)</td>
<td>Adult day service programmes (medical model vs. social model)</td>
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<td>Standard outcome measures: stress. Satisfaction with programme</td>
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<td>Reifler <em>et al.</em></td>
<td>50 sites providing adult day care centres</td>
<td>Selected from those applying to foundation for grants or technical assistance</td>
<td>Case series</td>
<td>Partners in Caregiving (PIC): the Dementia Services Programme (grants vs. technical assistance)</td>
<td>4-year period (1992–1996)</td>
<td>Service use and financial performance</td>
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# Table 2: In-home respite care (N = 4)

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<td>117</td>
<td>Milne et al. (1993)</td>
<td>Carers (78). Study group (63); control (15). Referring agents (numbers not given)</td>
<td>Elderly people (dementia and stroke were the two most common conditions)</td>
<td>Quantitative. Control group. Pre/3-month assessment</td>
<td>Age Concern Carer Support Scheme</td>
<td>Varied</td>
<td>Standard outcome measures: stress, strain, coping. Carer satisfaction questionnaire. Referrer satisfaction form</td>
<td>UK</td>
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<tr>
<td>214</td>
<td>Gwyther (1989)</td>
<td>Patient–carer pairs (40)</td>
<td>Dementia</td>
<td>Quantitative. No control. Pre-/post tests</td>
<td>In-home respite care</td>
<td>Varied</td>
<td>Satisfaction with service. Other outcomes measures (not described in detail)</td>
<td>USA</td>
</tr>
<tr>
<td>Study number</td>
<td>Author(s)</td>
<td>Sample</td>
<td>Care recipient group</td>
<td>Research methods</td>
<td>Intervention</td>
<td>Duration of intervention</td>
<td>Outcomes</td>
<td>Setting</td>
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<tr>
<td>4</td>
<td>Goldman <em>et al.</em> (1993)</td>
<td>Parents (c. 32 over 3 years); campers (c.31); graduate students/psychiatry residents (c.7)</td>
<td>Serious mental illness</td>
<td>Quantitative. No control group. No pre-test</td>
<td>Annual ‘respite camp’ for all family members</td>
<td>One week</td>
<td>Ratings forms: programme/camp evaluation</td>
<td>USA</td>
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<tr>
<td>50</td>
<td>Larkin and Hopcroft (1993)</td>
<td>Carers (22); patients (21)</td>
<td>Alzheimer’s disease</td>
<td>Quantitative. No control group. Pre-/post-tests. Follow up (14 days after discharge)</td>
<td>Hospital respite programme</td>
<td>2-week inpatient stay on 3 monthly basis</td>
<td>Standard outcome measures: carer stress. Carer satisfaction with service; receptivity to long-term inpatient placement.</td>
<td>USA</td>
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</table>
Table 3 Institutional respite (continued)

<table>
<thead>
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<th>Study number</th>
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<th>Outcomes</th>
<th>Setting</th>
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<tbody>
<tr>
<td>182</td>
<td>Watkins and Redfern (1997)</td>
<td>Patients (34); carers (27)</td>
<td>Dementia</td>
<td>Mixed. Case study approach. No control. Measures within one week of first attendance; then 6 weeks, 12 weeks, 6 months</td>
<td>CREST night nursing service</td>
<td>Varied</td>
<td>Standard outcome measures: coping; anxiety. Service evaluation</td>
<td>UK</td>
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<tr>
<td>189</td>
<td>Geiser et al. (1988)</td>
<td>Patients (14)</td>
<td>Mental illness</td>
<td>Mixed. No control. No pre-/post-tests</td>
<td>Respite care</td>
<td>2–7 day inpatient hospitalisation at 6–8-week intervals</td>
<td>Chart review; subject data from families: impact of respite programme on number of in-patient days; benefits of programme to carer</td>
<td>USA</td>
</tr>
<tr>
<td>Study number</td>
<td>Author(s)</td>
<td>Sample</td>
<td>Care recipient group</td>
<td>Research methods</td>
<td>Intervention</td>
<td>Duration of intervention</td>
<td>Outcomes</td>
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<td>9</td>
<td>Berry et al. (1991)</td>
<td>Female carers (40): Home care (20); day care (20)</td>
<td>Dementia</td>
<td>Quantitative. No control. Tests at baseline, and 5 subsequent occasions</td>
<td>Home care respite services. Comparator: day care respite services</td>
<td>About 19 hours/week</td>
<td>Standard outcome measures: burden; quality of caring relationship; daily activities; use of time. Satisfaction with programme</td>
<td>USA</td>
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<tr>
<td>10</td>
<td>Lawton et al. (1989)</td>
<td>Carers (632): experimental group (317); control group (315)</td>
<td>Alzheimer’s disease and related conditions</td>
<td>Quantitative. Randomised controlled trial. Pre-/post tests</td>
<td>Respite Demonstration Programme (Philadelphia)</td>
<td>12 months</td>
<td>Standard outcome measures: burden/satisfaction; physical health; mental health</td>
<td>USA</td>
</tr>
<tr>
<td>39</td>
<td>Koffman and Taylor (1997/8)</td>
<td>Carers (12)</td>
<td>Dementia</td>
<td>Qualitative</td>
<td>Respite care</td>
<td>Varied</td>
<td>Discussion about carers’ views on services</td>
<td>UK</td>
</tr>
<tr>
<td>64</td>
<td>Kosloski and Montgomery (1992)</td>
<td>Carers (114). Respite users (87); non-users (27)</td>
<td>Alzheimer’s disease</td>
<td>Quantitative. Control group. Post-tests</td>
<td>Michigan Model Projects Specialized Respite Care Programme</td>
<td>Varied</td>
<td>Structured questionnaire to evaluate the influence of attitudes on respite use</td>
<td>USA</td>
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<tr>
<td>81</td>
<td>Cotrell (1996)</td>
<td>Carers (100)</td>
<td>Dementia</td>
<td>Qualitative. No control. No pre-/post-tests</td>
<td>Respite services</td>
<td>Not given</td>
<td>Use of respite; preferences for methods of service delivery; perceptions of services</td>
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### Table 4 Mixed-respite care services (continued)

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<thead>
<tr>
<th>Study number</th>
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<th>Intervention</th>
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<th>Setting</th>
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<tbody>
<tr>
<td>85</td>
<td>Cox (1997)</td>
<td>Carers (228); Users (123); stoppers (55); non-users (50)</td>
<td>Alzheimer's disease or related disorder</td>
<td>Quantitative. Control. Pre-interviews. Follow-up (6 months)</td>
<td>Respite care</td>
<td>Varied</td>
<td>Standard outcome measures: quality of family relationships; use of services; carer need; problem behaviours; burden; well-being; coping ability; competency</td>
<td>USA</td>
</tr>
<tr>
<td>86</td>
<td>Gibbins (1986)</td>
<td>Patients (68); carers (73)</td>
<td>Elderly people with dementia, depression or anxiety</td>
<td>Mixed. No control. Pre-tests. Follow up repeats.</td>
<td>Oundle Community Care Unit (day and night centre)</td>
<td>Varied.</td>
<td>Standard outcome measures: strain; stress; problem behaviours</td>
<td>UK</td>
</tr>
<tr>
<td>93</td>
<td>Conlin et al. (1992)</td>
<td>Carers (15); respite users (7); control/non-users (8)</td>
<td>Alzheimer’s disease or related dementia</td>
<td>Quantitative. Control group. Pre-/post-tests.</td>
<td>Respite care</td>
<td>Respite of 6–8 hours/day, 2 days/week, for 10 weeks</td>
<td>Standard outcome measures: stress and mood disturbances</td>
<td>USA</td>
</tr>
<tr>
<td>153</td>
<td>Strang and Haughey (1998)</td>
<td>Carers (10)</td>
<td>Dementia</td>
<td>Qualitative</td>
<td>Respite services</td>
<td>Varied</td>
<td>Carers’ experiences of respite, including acceptability/benefit of services</td>
<td>Canada</td>
</tr>
<tr>
<td>154</td>
<td>Cox (1998)</td>
<td>Carers (228); users (123); stoppers (55); non-users (50)</td>
<td>Alzheimer’s disease or related disorder</td>
<td>Quantitative. Control. Pre-interviews. Follow-up (6 months)</td>
<td>Respite care</td>
<td>Varied</td>
<td>Standard outcome measures: quality of family relationships; use of services; carer need; problem behaviours; burden; well-being; coping ability; competency</td>
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## Table 4 Mixed-respite care services (continued)

<table>
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<th>Duration of intervention</th>
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<tbody>
<tr>
<td>201</td>
<td>Donaldson and Gregson (1989)</td>
<td>EMI patients (105); 35 intervention (24 carers); 70 controls (29 carers)</td>
<td>Elderly mentally infirm (EMI)</td>
<td>Quantitative. Case series with matched controls. Pre-/post-tests</td>
<td>Family support unit (co-ordinated and flexible community care)</td>
<td>Varied</td>
<td>Costs, benefits and effects of providing care for carers</td>
<td>UK</td>
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## Table 5  Education (N = 29)

<table>
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<th>Study number</th>
<th>Author(s)</th>
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<th>Care recipient group</th>
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<th>Intervention</th>
<th>Duration of intervention</th>
<th>Outcomes</th>
<th>Setting</th>
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<tbody>
<tr>
<td>14</td>
<td>Kahan et al. (1985)</td>
<td>Carers (40): study group (22); wait list/control group (18)</td>
<td>Alzheimer’s disease and related disorders</td>
<td>Quantitative. Control group. Pre- and post-tests</td>
<td>Specifically designed group support programme</td>
<td>8 weekly 2-hour sessions</td>
<td>Standard outcome measures: family burden; depression; knowledge of dementia. Programme evaluation</td>
<td>USA</td>
</tr>
<tr>
<td>18</td>
<td>Dixon et al. (2001)</td>
<td>Family members (37)</td>
<td>Mental illness</td>
<td>Quantitative. No control. Prospective longitudinal evaluation (follow-up at 6 months). Pre/post-tests</td>
<td>Family-to-Family Education Programme</td>
<td>12 weekly 2–3-hour sessions</td>
<td>Standard outcome measures: burden; empowerment; self-esteem; sense of mastery; social network; depression; physical health</td>
<td>USA</td>
</tr>
<tr>
<td>19</td>
<td>Chiverton and Caine (1989)</td>
<td>Carers (40): study group (20); control group (20)</td>
<td>Alzheimer’s disease</td>
<td>Quantitative. Control group. Pre-/post-tests</td>
<td>Educational programme</td>
<td>3 sessions of 2 hours</td>
<td>Standard outcome measure: family coping</td>
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### Table 5  Education (continued)

<table>
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<th>Study number</th>
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<th>Research methods</th>
<th>Intervention</th>
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<th>Outcomes</th>
<th>Setting</th>
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<tbody>
<tr>
<td>20</td>
<td>Abramowitz and Coursey (1989)</td>
<td>Carers (48); study group (24); wait list control group (24)</td>
<td>Schizophrenia</td>
<td>Quantitative. Matched controls. Pre-/post-tests</td>
<td>Educational support group</td>
<td>6 weekly 2-hour sessions</td>
<td>Standard outcome measures: trait anxiety; personal distress; negative feelings toward patient; life upset; use of community resources; generalised self-efficacy. Intervention evaluation</td>
<td>USA</td>
</tr>
<tr>
<td>30</td>
<td>Peternelj-Taylor and Hartley (1993)</td>
<td>Family/friends (370)</td>
<td>Mentally ill</td>
<td>Quantitative. Self-administered evaluation</td>
<td>‘Living with mental illness’ workshop for families and friends</td>
<td>One day (8 hours)</td>
<td>Workshop evaluation</td>
<td>USA</td>
</tr>
<tr>
<td>43</td>
<td>Mort et al. (1993)</td>
<td>Carers (23)</td>
<td>Dementia</td>
<td>Quantitative. No control group. Pre-/post tests (at 6 months)</td>
<td>Educational programme</td>
<td>Not clear; possibly one session</td>
<td>Structured interview guide focusing on problem behaviours and psychotropic medications</td>
<td>USA</td>
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### Table 5  Education (continued)

<table>
<thead>
<tr>
<th>Study number</th>
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<th>Sample</th>
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<th>Research methods</th>
<th>Intervention</th>
<th>Duration of intervention</th>
<th>Outcomes</th>
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<tbody>
<tr>
<td>72</td>
<td>Pickett-Schenk et al. (2000)</td>
<td>Families (424)</td>
<td>Mental illness</td>
<td>Quantitative, National survey</td>
<td>Journey of Hope Educational Programme</td>
<td>12 weeks</td>
<td>Evaluation of programme outcomes, Satisfaction with programme</td>
<td>USA</td>
</tr>
<tr>
<td>75</td>
<td>Toth-Cohen (2000)</td>
<td>Occupational therapists (4)</td>
<td>Dementia</td>
<td>Qualitative</td>
<td>Occupational therapists' support and education for carers in the community</td>
<td>Varied</td>
<td>Therapists' self-perceptions as educators/supporters of carers</td>
<td>USA</td>
</tr>
<tr>
<td>76</td>
<td>Steffen et al. (1999)</td>
<td>Carers (51), Telephone survey (35), Focus groups (16) (8 carers; 8 professionals)</td>
<td>Alzheimer's disease and related diseases</td>
<td>Mixed survey and focus groups</td>
<td>How to Cope educational programme</td>
<td>4 weekly 2-hour sessions</td>
<td>Evaluation of programme, Participant satisfaction</td>
<td>USA</td>
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<tr>
<td>80</td>
<td>Zanetti et al. (1998)</td>
<td>Carers (23), Study group (12); control group = 9</td>
<td>Dementia</td>
<td>Quantitative, Control group, Pre-/post-tests, Follow-up (3 months)</td>
<td>Educational programme</td>
<td>6 sessions of one hour</td>
<td>Standard outcome measures: depression; stress; quality of life; knowledge of disease</td>
<td>Italy</td>
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<tr>
<td>102</td>
<td>Birchwood et al. (1992)</td>
<td>Relatives (94), Group (47); post (30); video (17)</td>
<td>Schizophrenia</td>
<td>Quantitative, No control group, Pre-/post tests, Follow-up (6 months)</td>
<td>Three methods of delivering educational interventions: information given in a group; by post; by video</td>
<td>Weekly for 4 weeks</td>
<td>Standard outcome measures: knowledge; beliefs and expectations; stress; burden; patient disturbance; social functioning</td>
<td>UK</td>
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Table 5 Education (continued)

<table>
<thead>
<tr>
<th>Study number</th>
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<th>Research methods</th>
<th>Intervention</th>
<th>Duration of intervention</th>
<th>Outcomes</th>
<th>Setting</th>
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<tbody>
<tr>
<td>113</td>
<td>Reinhard (1994)</td>
<td>Carers (94)</td>
<td>Severe mentally illness</td>
<td>Quantitative. No control group. Post-tests</td>
<td>Provision of information from professionals</td>
<td>Varied</td>
<td>Standard outcome measures: sense of control; depression; carer burden; well-being; professional support; disruptive behaviours</td>
<td>USA</td>
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<tr>
<td>120</td>
<td>Burgener et al. (1998)</td>
<td>Patient–carer pairs. Total intervention = 11 pairs; educational programme = 12 pairs; behavioural intervention programme = 12 pairs; control group = 12 pairs</td>
<td>Alzheimer’s disease or related dementia</td>
<td>Quantitative. Control group. Pre-/post-tests (6 months)</td>
<td>Education programme. Comparator: behaviour intervention programme</td>
<td>One session of approx 90 minutes</td>
<td>Standard outcome measures: knowledge of dementia; stress</td>
<td>USA</td>
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Table 5  Education (continued)

<table>
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<tr>
<th>Study number</th>
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<th>Research methods</th>
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<th>Duration of intervention</th>
<th>Outcomes</th>
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<tr>
<td>131</td>
<td>Bedard et al. (1997)</td>
<td>Patient–carer pairs (111)</td>
<td>Cognitive impairment</td>
<td>Quantitative. No control. Pre-and post-tests</td>
<td>Standard medical intervention, including education of carers</td>
<td>Short</td>
<td>Standard outcome measures: carer burden; health; time demands from caring; informal social support</td>
<td>Canada</td>
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<td>140</td>
<td>Coen et al. (1999)</td>
<td>Carers (32)</td>
<td>Dementia</td>
<td>Quantitative. No control. Pre-/post tests (6 months)</td>
<td>Carer Education Programme</td>
<td>8 weekly 2-hour sessions</td>
<td>Standard outcome measures: quality of life; burden; well-being; patient problem behaviours; informal social support</td>
<td>Ireland</td>
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<tr>
<td>145</td>
<td>Magni et al. (1995)</td>
<td>Carers (22)</td>
<td>Dementia</td>
<td>Quantitative. No control. Pre-/post tests</td>
<td>Educational programme</td>
<td>8 weekly 2-hour sessions</td>
<td>Standard outcome measures: stress, depression, knowledge</td>
<td>Italy</td>
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<tr>
<td>159</td>
<td>Matthew (1990)</td>
<td>Carers (32)</td>
<td>Dementia</td>
<td>Mixed (questionnaire and follow-up interviews). No control. Post-test</td>
<td>Community psychiatric nurses as communicators and information providers</td>
<td>Not clear</td>
<td>Evaluation of CPNs' effectiveness in communicating information to carers</td>
<td>UK</td>
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<tr>
<td>Study number</td>
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<td>Research methods</td>
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<td>Duration of intervention</td>
<td>Outcomes</td>
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<tr>
<td>162</td>
<td>Russell et al. (1989)</td>
<td>Carers (5)</td>
<td>Dementia</td>
<td>Quantitative. No control. Pre-/post-tests</td>
<td>Relatives Support Group</td>
<td>6 weeks</td>
<td>Standard outcome measures: disturbing behaviours; emotional distress; strain; depression</td>
<td>UK</td>
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<tr>
<td>164</td>
<td>Brooker et al. (1992)</td>
<td>Families (30). Study group (17); control (13)</td>
<td>Schizophrenia</td>
<td>Quantitative. Pre-/post-tests. Follow-up (6 months)</td>
<td>Education about the nature of schizophrenia by community psychiatric nurses.</td>
<td>Standard outcome measures: functional knowledge about schizophrenia</td>
<td>UK</td>
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<tr>
<td>168</td>
<td>Dura (1993)</td>
<td>Carer (1)</td>
<td>Huntington’s disease</td>
<td>Quantitative. Pre-/post-tests. Follow up (one month)</td>
<td>Educational intervention</td>
<td>4 2-hour sessions</td>
<td>Standard outcome measures: depression; affective states; confidence in ability to assist; behaviour problems; knowledge. Programme evaluation</td>
<td>USA</td>
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Table 5  Education (continued)

<table>
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<tr>
<th>Study number</th>
<th>Author(s) (year)</th>
<th>Sample</th>
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<th>Research methods</th>
<th>Intervention</th>
<th>Duration of intervention</th>
<th>Outcomes</th>
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<tr>
<td>272</td>
<td>Smith and Birchwood</td>
<td>Family members (40). Group condition 20.</td>
<td>Group condition 20.</td>
<td>Quantitative. No control. Pre-/post-tests. Follow-up (6 months)</td>
<td>Educational intervention delivered in two different formats (by professional in a group; in booklet form through post)</td>
<td>4-weekly sessions</td>
<td>Standard outcome measures: knowledge acquisition; beliefs about schizophrenia and its treatment; worry and fear; behavioural disturbance; stress; family distress</td>
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<td>286</td>
<td>Mullen et al. (1992)</td>
<td>Relatives (13)</td>
<td>Chronic mental illness</td>
<td>Quantitative. No control. Post-test</td>
<td>Workshop</td>
<td>One 90-minute meeting</td>
<td>Questionnaire on impact of workshop on understanding of: service operation; patient problems; caring role</td>
<td>UK</td>
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<tr>
<td>287</td>
<td>Sidley et al. (1991)</td>
<td>Relatives (18). Modified educational package (9); original educational package (9)</td>
<td>Schizophrenia</td>
<td>Quantitative. Pre-/post-tests. No control</td>
<td>‘Modified’ education package. Comparator: ‘original’ education package</td>
<td>2 90-minute group sessions</td>
<td>Standard outcome measures: functional value of knowledge of schizophrenia; factual knowledge; stress symptoms; family distress; patient disturbance</td>
<td>UK</td>
</tr>
<tr>
<td>Study number</td>
<td>Author(s)</td>
<td>Sample</td>
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<td>Research methods</td>
<td>Intervention</td>
<td>Duration of intervention</td>
<td>Outcomes</td>
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<td>66</td>
<td>Gendron et al. (1996)</td>
<td>Carers (35). C–B group (18); support group (17)</td>
<td>Dementia</td>
<td>Quantitative. No control. Pre-/post tests. Follow-up (3 and 6 months)</td>
<td>Cognitive–behavioural group intervention C–B). Comparator: support group</td>
<td>8 weekly sessions of 90 minutes</td>
<td>Standard outcome measures: psychological distress; depression; coping; marital adjustment; burden. Programme evaluation questionnaire</td>
<td>Canada</td>
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</table>
### Table 6  Training (continued)

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

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

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

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<tr>
<td>155</td>
<td>Robinson (1988)</td>
<td>Carers (20). Study group (11); control group (9)</td>
<td>Alzheimer’s disease or related disorder</td>
<td>Quantitative. Control group. Pre-/post-tests</td>
<td>Social skills training programme</td>
<td>4 2-hour sessions</td>
<td>Standard outcome measures: Carer burden, self-esteem, social skills, social support. Programme evaluation</td>
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<td>Study number</td>
<td>Author(s)</td>
<td>Sample</td>
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<td>Research methods</td>
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<td>179</td>
<td>Seltzer et al. (1992)</td>
<td>Patients and family members (143 pairs); Dementia (58 pairs); haemodialysis (85 pairs)</td>
<td>Elderly patients with dementia (55+ years); Elderly patients needing dialysis (60+ years)</td>
<td>Quantitative. Control group. Pre-/post-tests</td>
<td>Case management training (Family Centred Community Care for the Elderly)</td>
<td>6 months</td>
<td>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</td>
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<tr>
<td>180</td>
<td>Kilstoff and Chenoweth (1998)</td>
<td>Total sample (39). Clients (16); carers (16); day care staff (7)</td>
<td>Dementia</td>
<td>Qualitative; action research. In-depth interviews pre-/post treatment</td>
<td>Gentle hand treatment for dementia day care clients using three essential oils</td>
<td>15-minute treatments</td>
<td>In-depth interviews; focus group discussions; client observations logbooks. Evaluation of hand treatment programme</td>
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<tr>
<td>184</td>
<td>Quayhagen and Quayhagen (1996)</td>
<td>Patient–carer pairs (10 pairs)</td>
<td>Dementia</td>
<td>Qualitative. No control. Pre-/post tests. Follow-up (8 months)</td>
<td>Cognitive remediation intervention</td>
<td>8 fortnightly sessions for 4 months</td>
<td>Efficacy of intervention: interviews; observation, care-giver log recordings; semi-structured evaluation forms</td>
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### Table 6  Training (continued)

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<th>Outcomes</th>
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<tbody>
<tr>
<td>188</td>
<td>Ripich et al. (1999)</td>
<td>Carers (54). FOCUSED study group (22); FOCUSED-Booster study group (10); control group (22)</td>
<td>Alzheimer’s disease: early–midstage</td>
<td>Quantitative. Control group. Pre-/post-tests. Follow-up (6/12 months)</td>
<td>FOCUSED communication training. FOCUSED-Booster training</td>
<td>FOCUSED: 8 hours over 4 weeks. FOCUSED-Booster Follow-up: reinforcers at 4 months, 8 months, and 11 months after entry</td>
<td>Communication task (planning a menu); observation of communication</td>
<td>USA</td>
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<tr>
<td>196</td>
<td>Brodaty et al. (1991)</td>
<td>Patient-carer pairs (96 pairs). Immediate carer training (33). 6-month delayed carer training (32). Patient memory retraining/no training for carers = 31</td>
<td>Dementia (mild to moderate)</td>
<td>Quantitative. Control group. Pre-/post-tests. Follow-up (to 3 years)</td>
<td>10-day residential care-giver training Programme; 10-day memory retraining programme for patients</td>
<td>10 days</td>
<td>Standard outcome measures: carer stress; neuroticism; satisfaction. Impact of training on nursing home admission and/or survival to death</td>
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Table 7  Psychoeducational interventions (N = 23)

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<th>Outcomes</th>
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<tr>
<td>2</td>
<td>Pakenham and Dadds (1987)</td>
<td>Parents (7)</td>
<td>Schizophrenia (18–40 years)</td>
<td>Quantitative. No control group. Pre-/post-tests</td>
<td>Supportive/educational programme</td>
<td>9 weekly sessions of 2 hours</td>
<td>Standard outcome measures: knowledge; behavioural disturbances; psychological health; coping. Consumer needs questionnaire</td>
<td>Australia</td>
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<tr>
<td>5</td>
<td>Buckwalter et al. (1999)</td>
<td>Carers (240). Study (132); comparison (108)</td>
<td>Alzheimer’s disease and related dementias</td>
<td>Quantitative. Pre-/post-tests (at 3–6 months). Follow-up (12 months)</td>
<td>Community-based psycho-educational-nursing intervention. Comparator: routine support</td>
<td>6 months</td>
<td>Standard outcome measures: carer affect, depression</td>
<td>USA</td>
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<tr>
<td>16</td>
<td>Hepburn et al. (2001)</td>
<td>Families (117). Study group (72); wait list control (45)</td>
<td>Dementia (mild–severe)</td>
<td>Quantitative. Control group. Pre-/post-tests. Follow-up (5 months)</td>
<td>Care-giver role training (Minnesota Family Workshop)</td>
<td>2-hour sessions for 7 weeks</td>
<td>Standard outcome measures: depression, burden, problem behaviours</td>
<td>USA</td>
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<tr>
<td>21</td>
<td>Bland and Harrison (2000)</td>
<td>Carers (15)</td>
<td>Bipolar disorder</td>
<td>Quantitative. No control. Pre-/post tests. Follow-up (3 months)</td>
<td>Psycho-educational programme</td>
<td>Not clear</td>
<td>Standard outcome measures: knowledge; distress; social support; coping; attribution of cause of symptoms. Programme evaluation</td>
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<tr>
<td>Study number</td>
<td>Author(s)</td>
<td>Sample</td>
<td>Care recipient group</td>
<td>Research methods</td>
<td>Intervention</td>
<td>Duration of intervention</td>
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<td>22</td>
<td>Hugen (1993)</td>
<td>Family members (22)</td>
<td>Schizophrenia</td>
<td>Quantitative. No control group. Pre-/post-tests</td>
<td>Educational workshop</td>
<td>One day</td>
<td>Standard outcome measures: knowledge; attitudinal change. Relapse rates. Satisfaction with workshop</td>
<td>USA</td>
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<tr>
<td>48</td>
<td>Ostwald et al. (1999)</td>
<td>Families (117); study group (72); wait list control (45)</td>
<td>Dementia (mild to severe)</td>
<td>Quantitative. Control group Pre-/post-tests. Follow up (5 months)</td>
<td>Psycho-educational family group intervention (Minnesota Family Workshop)</td>
<td>2 hours sessions for 7 weeks</td>
<td>Standard outcome measures: depression, burden, problem behaviours</td>
<td>USA</td>
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<tr>
<td>54</td>
<td>Mannion et al. (1994)</td>
<td>Carers (19)</td>
<td>Serious mental illness</td>
<td>Quantitative. No control. Pre-/post-tests. Follow-up (12 months)</td>
<td>Group psychoeducational approach for spouses.</td>
<td>2-hour meetings over 10 weeks</td>
<td>Standard outcome measures: knowledge; personal distress; attitudes; coping</td>
<td>USA</td>
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Table 7  Psychoeducational interventions (continued)

<table>
<thead>
<tr>
<th>Study number</th>
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<th>Research methods</th>
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<th>Outcomes</th>
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<tbody>
<tr>
<td>56</td>
<td>Gallagher-Thompson and DeVries (1994)</td>
<td>Carers (48)</td>
<td>Alzheimer’s disease or related dementia</td>
<td>Quantitative. Part of a larger study. Pre-/post-tests; follow-up (18 months)</td>
<td>Anger management class (one component of psychoeducational programme)</td>
<td>2 hours for 8 weeks + 2 booster sessions</td>
<td>Standard outcome measures: carer stress, burden, negative effect</td>
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<tr>
<td>58</td>
<td>McFarland and Sanders (2000)</td>
<td>Carers (11)</td>
<td>Alzheimers disease</td>
<td>Qualitative. No control</td>
<td>Educational support groups for male carers.</td>
<td>One weekday evening for 4 weeks</td>
<td>Evaluation of group process and format in relation to accomplishment of group objectives</td>
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<tr>
<td>68</td>
<td>Sherrill et al. (1997)</td>
<td>Family members (182); patients (132)</td>
<td>Elderly patients with recurrent major depression</td>
<td>Quantitative. No control. Pre-/post-measures (for patients only)</td>
<td>Family psychoeducational workshop</td>
<td>One day</td>
<td>Evaluation of content and quality of workshop</td>
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<tr>
<td>69</td>
<td>Zhang et al. (1998)</td>
<td>Carers (1048). Study group (682); control group (366)</td>
<td>Schizophrenia</td>
<td>Quantitative. Control group. Pre-/post-tests. Follow-up (2 years)</td>
<td>Group psychoeducational programme</td>
<td>10 sessions in year 1; 4 in year 2</td>
<td>Standard outcome measures: burden, mental and physical health status, knowledge of caring</td>
<td>China</td>
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Table 7  Psychoeducational interventions (continued)

<table>
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<tr>
<th>Study number</th>
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<th>Research methods</th>
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<tr>
<td>70</td>
<td>Cummings et al. (1998)</td>
<td>Carers (13)</td>
<td>Early stage Alzheimer’s disease</td>
<td>Quantitative. No control group. Pre-/post-measures</td>
<td>Psychoeducational support group</td>
<td>8 weekly sessions of 90 minutes</td>
<td>Standard outcome measures: stress, adaptive functioning; competency and self-confidence; beliefs about caring role; coping behaviours</td>
<td>USA</td>
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<tr>
<td>79</td>
<td>Cummings (1996)</td>
<td>Carer case examples (4)</td>
<td>Early stage Alzheimer’s disease</td>
<td>Not given (but see study no 70 above)</td>
<td>Psychoeducational support group</td>
<td>Eight weekly sessions of 90 minutes</td>
<td>Not given (but see study no 70 above)</td>
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<td>87</td>
<td>Woods et al. (1998)</td>
<td>Carers (104)</td>
<td>ANS (55); CPN/CMHT (49); Admiral Nurses and CPNs; Team leaders</td>
<td>Dementia</td>
<td>Mixed. No control. Pre-/post-tests (at 8 months)</td>
<td>Admiral Nurse Service (ANS). Comparator: CPN/Community Teams for Mental Health for Older People</td>
<td>8 months</td>
<td>Standard outcome measures: quality of relationship; strain and distress; behavioural problems; need. Service questionnaire: frequency and satisfaction</td>
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<tr>
<td>104</td>
<td>Solomon and Draine (1995)</td>
<td>Family members (225). Individual consultation (66); group family workshop (67); waiting list control group (92)</td>
<td>Schizophrenia or major affective disorder</td>
<td>Quantitative. Random assignment to study conditions or control group. Pre-/post-tests. Follow-up (6 months)</td>
<td>Individual Family Consultation. Comparator: Group Family Workshop</td>
<td>3 months</td>
<td>Standard outcome measures: burden; patient’s level of functioning; social support, self-efficacy; satisfaction with coping</td>
<td>USA</td>
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<tr>
<td>Study number</td>
<td>Author(s)</td>
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<td>Outcomes</td>
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<td>105</td>
<td>North et al. (1998)</td>
<td>Relatives/patient s (80). Family workshops (56); multiple family groups (24)</td>
<td>Schizophrenia</td>
<td>Quantitative. No control. Pre-/post-tests</td>
<td>Multifamily Psychoeducational Programme</td>
<td>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</td>
<td>Standard outcome measures: ability to manage; knowledge; disruptions to family life. Hospital admissions/days. Number of days lost from work. Satisfaction questionnaire</td>
<td>USA</td>
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<tr>
<td>106</td>
<td>Solomon et al. (1997)</td>
<td>Family members (225). Individual consultation (66); group family workshop (67); wait list control (92)</td>
<td>Schizophrenia or major affective disorder</td>
<td>Quantitative. Random assignment to study conditions or control group. Pre-/post-tests. Follow-up (6 months)</td>
<td>Individual Family Consultation. Comparator: Group Family Workshop</td>
<td>3 months</td>
<td>Standard outcome measures: burden; patient’s level of functioning; social support, self-efficacy; satisfaction with coping</td>
<td>USA</td>
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<tr>
<td>107</td>
<td>Posner et al. (1992)</td>
<td>Family members (55). Study group (28); wait list/control (27)</td>
<td>Schizophrenia (patients 40 years of age or younger)</td>
<td>Quantitative. Control group. Pre-/post-tests. Follow-up (6 months)</td>
<td>Family psychoeducational support group</td>
<td>8 weekly sessions of 90 minutes</td>
<td>Standard outcome measures: knowledge of schizophrenia; family satisfaction; negative feelings for patient; coping behaviours; psychological distress. Consumer satisfaction with health care services</td>
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Table 7  Psychoeducational interventions (continued)

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<th>Research methods</th>
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<th>Duration of intervention</th>
<th>Outcomes</th>
<th>Setting</th>
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<td>148</td>
<td>Brodaty <em>et al.</em> (1994)</td>
<td>Carers (81). Completers group (33); Non/partial completers (22); control group (26). Coordinators = 21</td>
<td>Dementia</td>
<td>Mixed. Control. Pre-/post-tests</td>
<td>Group education programme</td>
<td>18 hours over 4 months</td>
<td>Standard outcome measures: carer burden; psychological stress; satisfaction with life; well-being; knowledge</td>
<td>Australia</td>
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<td>174</td>
<td>Shimodera <em>et al.</em> (2000)</td>
<td>Pts (87); high-EE (38); low-EE (49). Close family members (111). SES + SFT group (13) pts/families. SES group (17 pts/families)</td>
<td>Schizophrenia</td>
<td>Quantitative. High-EE families randomly allocated to SES or SES+ SFT. Pre-/post-tests. Follow-up (9 months</td>
<td>Short education sessions (SES) in high-EE households. Comparator: short education sessions + single-family treatment in high-EE households</td>
<td>Once every 2 weeks for 9 months</td>
<td>Standard outcome measures: EE. Risk of relapse</td>
<td>Japan</td>
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## Table 8 Family interventions (N = 20)

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<th>Study number</th>
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<tr>
<td>40</td>
<td>Barrowclough et al. (1999)</td>
<td>Patient–carer pairs (77 pairs). Study group (38); control group (39)</td>
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<td>60</td>
<td>Mitrani and Czaja (2000)</td>
<td>Carers (224), assigned to one of two study conditions or control group</td>
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<td>92</td>
<td>Weinberg and Huxley (2000)</td>
<td>Carers (62). FSWs (15); co-professionals (15)</td>
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<td>99</td>
<td>McCreadie et al. (1991)</td>
<td>Carers (31)</td>
</tr>
<tr>
<td>101</td>
<td>Leff et al. (1990)</td>
<td>Relatives (23 families). Family therapy + education (12). Relatives group + education (11)</td>
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<th>Research methods</th>
<th>Intervention</th>
<th>Duration of intervention</th>
<th>Outcomes</th>
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<tr>
<td>Schizophrenia</td>
<td>Quantitative. Randomised controlled pragmatic trial. Pre-/post-tests</td>
<td>Needs-based cognitive–behavioural family intervention</td>
<td>24 weeks</td>
<td>Standard outcome measures; cardinal needs; psychological distress; depression; social behaviour</td>
<td>UK</td>
</tr>
<tr>
<td>Dementia</td>
<td>Quantitative. Randomised controlled trial</td>
<td>Family-based therapy (SET). Comparator: SET + computer integrated telepone system</td>
<td>12 months</td>
<td>Family interactional patterns</td>
<td>USA</td>
</tr>
<tr>
<td>FSWs</td>
<td>Mixed. No control. Post-test only</td>
<td>Treatment package (educational seminars; relatives’ groups; family meetings)</td>
<td>Varied</td>
<td>Standard outcome measures: quality of life; burden. Diary study of activities undertaken by FSWs. Co-professionals’ evaluation of satisfaction with FSWs</td>
<td>UK</td>
</tr>
<tr>
<td>Schizophrenia</td>
<td>Quantitative. No control group. Pre-/post-tests. Follow-up (2 years)</td>
<td>Family therapy: fortnightly, for 9 months</td>
<td></td>
<td>Standard outcome measures: EE; knowledge. Time budgets. Relapse rates</td>
<td>UK</td>
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</table>
### Table 8  Family interventions (continued)

<table>
<thead>
<tr>
<th>Study number</th>
<th>Author(s)</th>
<th>Sample</th>
<th>Care recipient group</th>
<th>Research methods</th>
<th>Intervention</th>
<th>Duration of intervention</th>
<th>Outcomes</th>
<th>Setting</th>
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<tbody>
<tr>
<td>103</td>
<td>Falloon and Pederson (1985)</td>
<td>Patients (36); parents (56). Family management group (18). Individual management group= 18</td>
<td>Schizophrenia</td>
<td>Quantitative. No control group. Testing at baseline and pre-determined intervals over 2 years</td>
<td>Family management of schizophrenia. Comparator: individual management</td>
<td>24 months</td>
<td>Standard outcome measures; psychopathology, social adjustment, family distress and burden; family coping functions</td>
<td>UK</td>
</tr>
<tr>
<td>108</td>
<td>Xiong et al. (1994)</td>
<td>Families (63). Study group (34); control group (29)</td>
<td>Schizophrenia</td>
<td>Quantitative. Control group. Pre-/post-tests. Follow-up (18 months)</td>
<td>Family-based intervention</td>
<td>1–2 years</td>
<td>Standard outcome measures: family burden. Number and duration of hospitalisations</td>
<td>China</td>
</tr>
<tr>
<td>110</td>
<td>MacCarthy et al. (1989)</td>
<td>Patients/relatives (26 families). Study group (9); control group (17)</td>
<td>Severe mental illness</td>
<td>Quantitative. Control group. Pre-/post-tests</td>
<td>Interactive education sessions at home, followed by monthly relatives group</td>
<td>One year</td>
<td>Standard outcome measures: EE, burden, coping, knowledge</td>
<td>UK</td>
</tr>
<tr>
<td>112</td>
<td>Budd and Hughes (1997)</td>
<td>Relatives (20)</td>
<td>Schizophrenia</td>
<td>Qualitative. No control. Post-test only</td>
<td>Clinically based family intervention programme</td>
<td>Average 12 months</td>
<td>Semi-structured interviews: programme evaluation to identify helpful and unhelpful aspects</td>
<td>UK</td>
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### Table 8 Family interventions (continued)

<table>
<thead>
<tr>
<th>Study number</th>
<th>Author(s)</th>
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<th>Duration of intervention</th>
<th>Outcomes</th>
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<tbody>
<tr>
<td>116</td>
<td>Bentley (1990)</td>
<td>Patients (4); carers (4)</td>
<td>Schizophrenia</td>
<td>Quantitative. No control. Pre-/post tests. Follow-up (6 weeks)</td>
<td>In-home educational and skills training Programme</td>
<td>Twice weekly sessions for 5 weeks</td>
<td>Standard outcome measures: attitudes, family stress</td>
<td>USA</td>
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<tr>
<td>137</td>
<td>Hughes et al. (1996)</td>
<td>Presents 3 case studies</td>
<td>Serious mental illness</td>
<td>Not given</td>
<td>STEP family intervention</td>
<td>Average 12 months</td>
<td>Subjective ratings by therapists; case notes</td>
<td>UK</td>
</tr>
<tr>
<td>165</td>
<td>Razali et al. (2000)</td>
<td>Patients and carers (143). Study (CMFT) group (74); control group (BFT) (69)</td>
<td>Schizophrenia</td>
<td>Quantitative. Randomised controlled trial. Pre-/post-tests at 6 months. Follow-up (12 months)</td>
<td>Culturally Modified Family Therapy (CMFT). Comparator: Behavioural Family Therapy (BFT)</td>
<td>12 months</td>
<td>Standard outcome measures: family burden; psychosocial functioning; behavioural difficulties. Number of hospitalisations</td>
<td>Malaysia</td>
</tr>
<tr>
<td>172</td>
<td>Marley (1992)</td>
<td>Patients/ families (2)</td>
<td>Mentally ill</td>
<td>Qualitative</td>
<td>Family therapy intervention</td>
<td>Not stated</td>
<td>Effectiveness of intervention</td>
<td>USA</td>
</tr>
<tr>
<td>261</td>
<td>Tarrier et al. (1991)</td>
<td>Carers (73); high EE study group (25); high EE control group (29); low EE control group (19)</td>
<td>Schizophrenia</td>
<td>Quantitative. Control group. Pre-/post-tests</td>
<td>9-month family intervention. Comparator: short educational programme or routine care</td>
<td>9 months</td>
<td>Relapse rate in patients</td>
<td>UK</td>
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Table 8 Family interventions (continued)

<table>
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<th>Research methods</th>
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<tr>
<td>271</td>
<td>Szmukler et al. (forthcoming)</td>
<td>Carers (77). Study results based on sub-group (61); Study group (30); control group (31)</td>
<td>Psychotic disorder</td>
<td>Quantitative. Exploratory randomised controlled trial. Baseline tests; follow-up (16 months)</td>
<td>Family sessions, followed by relatives’ groups</td>
<td>9 months</td>
<td>Standard outcome measures: psychological morbidity; appraisal of caring; coping; social support</td>
<td>UK</td>
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<tr>
<td>274</td>
<td>Cardin et al. (1985)</td>
<td>Patients (36). Family management (18); individual management (18)</td>
<td>Schizophrenia</td>
<td>Quantitative. Randomised controlled trial. Pre-/post-tests</td>
<td>Family management. Comparator: individual supportive management</td>
<td>24 months</td>
<td>Standard outcome measures: family burden; carer satisfaction</td>
<td>USA</td>
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<tr>
<td>275</td>
<td>Kuipers et al. (1989)</td>
<td>Presents three case studies (but see study no. 110 above)</td>
<td>Severe mental illness</td>
<td>See study no. 110 above</td>
<td>Interactive education sessions at home, followed by a monthly relatives group</td>
<td>One year</td>
<td>Standard outcome measures: EE, burden, coping, knowledge</td>
<td>UK</td>
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<tr>
<td>Study number</td>
<td>Author(s) (year)</td>
<td>Sample</td>
<td>Care recipient group</td>
<td>Research methods</td>
<td>Intervention</td>
<td>Duration of intervention</td>
<td>Outcomes</td>
<td>Setting</td>
</tr>
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<td>3</td>
<td>Gonyea (1989)</td>
<td>Support group leaders (47). Support group members (301)</td>
<td>Alzheimer’s disease</td>
<td>Quantitative. No control group. Post-test</td>
<td>Alzheimer’s disease support groups</td>
<td>Varied</td>
<td>Questionnaire survey: strengths and weaknesses of support groups</td>
<td>USA</td>
</tr>
<tr>
<td>11</td>
<td>Hebert et al. (1994)</td>
<td>Carers (41); study group (23); control group (18)</td>
<td>Dementia</td>
<td>Quantitative. Randomised controlled trial. Pre-/post-tests. Follow-up (8 months)</td>
<td>Specially designed support group programme</td>
<td>8 weekly 3-hour sessions</td>
<td>Standard outcome measures: burden; knowledge; problem behaviours; health care utilisation. Satisfaction with programme</td>
<td>Canada</td>
</tr>
<tr>
<td>12</td>
<td>Hebert et al. (1995)</td>
<td>Carers (45); study group (24); control group (21)</td>
<td>Dementia</td>
<td>Follow-up of earlier study (see study no 11 above). Survival analysis</td>
<td>Specially designed support group programme</td>
<td>8 weekly 3-hour sessions</td>
<td>Impact of support group of institutionalisation of patient</td>
<td>Canada</td>
</tr>
<tr>
<td>13</td>
<td>Cook et al. (1999)</td>
<td>Carers (120); study (86); control (34)</td>
<td>Mental illness</td>
<td>Quantitative. Control group. Post-test</td>
<td>NAMI-affiliated support groups</td>
<td>Varied</td>
<td>Standard outcome measures: parental burden; depression; social support; service utilisation</td>
<td>USA</td>
</tr>
<tr>
<td>15</td>
<td>Gage and Kinney (1995)</td>
<td>Carers (79): attendees group (27); non-attendees group (52)</td>
<td>Dementia</td>
<td>Quantitative. Control (non-attendees) group. Post-test</td>
<td>Carer support groups</td>
<td>Varied</td>
<td>Standard outcome measures: hassles appraisals, coping efforts, well-being</td>
<td>USA</td>
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</table>
### Table 9  Mutual support and social activity groups (continued)

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

<table>
<thead>
<tr>
<th>Study number</th>
<th>Author(s)</th>
<th>Sample</th>
<th>Care recipient group</th>
<th>Research methods</th>
<th>Intervention</th>
<th>Duration of intervention</th>
<th>Outcomes</th>
<th>Setting</th>
</tr>
</thead>
<tbody>
<tr>
<td>122</td>
<td>Forde and Peariman (1999)</td>
<td>Not given</td>
<td>Alzheimer’s disease or related dementia</td>
<td>Observation and informal evaluation</td>
<td>Breakaway programme</td>
<td>Varied</td>
<td>Impact of programme. Programme satisfaction</td>
<td>USA</td>
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<tr>
<td>173</td>
<td>Winefield et al. (1998)</td>
<td>Carers (36) divided into 3 groups (pilot, treatment and waiting list control)</td>
<td>Chronic schizophrenia</td>
<td>Quantitative. Control group. Pre-/post tests. Follow-up (8 weeks)</td>
<td>Discussion group</td>
<td>8 sessions</td>
<td>Standard outcome measures: social support; psychological state; attitudes to the patient. Group evaluation</td>
<td>Australia</td>
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</table>
## Table 10  Counselling (N = 9)

<table>
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<th>Study number</th>
<th>Author(s)</th>
<th>Sample</th>
<th>Care recipient group</th>
<th>Research methods</th>
<th>Intervention</th>
<th>Duration of intervention</th>
<th>Outcomes</th>
<th>Setting</th>
</tr>
</thead>
<tbody>
<tr>
<td>45</td>
<td>Mittleman et al. (1995)</td>
<td>Carers (206). Study (103); control (103)</td>
<td>Alzheimer’s disease</td>
<td>Quantitative. Randomised treatment/control trial. Pre-/post-tests. Long-term follow-up (to 8 years)</td>
<td>Comprehensive support programme</td>
<td>6 sessions of counselling, followed by a weekly, continuous support group. Ongoing counselling available.</td>
<td>Standard outcome measures: carer depression; health; social support</td>
<td>USA</td>
</tr>
<tr>
<td>46</td>
<td>Mittleman et al. (1993)</td>
<td>Carers (206). Study (103); control (103)</td>
<td>Alzheimer’s disease</td>
<td>Quantitative. Randomised treatment/control trial. Pre-/post-tests. Long-term follow-up (to 8 years)</td>
<td>Comprehensive support programme</td>
<td>6 sessions of counselling, followed by a weekly, continuous support group. Ongoing counselling available</td>
<td>Standard outcome measures: carer burden; health; social support</td>
<td>USA</td>
</tr>
<tr>
<td>47</td>
<td>Mittleman et al. (1996)</td>
<td>Carers (206). Study (103); control (103)</td>
<td>Alzheimer’s disease</td>
<td>Quantitative. Randomised treatment/control trial. Pre-/post-tests. Long-term follow-up (to 8 years)</td>
<td>Comprehensive support programme</td>
<td>6 sessions of counselling, followed by a weekly, continuous support group. Ongoing counselling available</td>
<td>Standard outcome measures: carer depression; health; social support</td>
<td>USA</td>
</tr>
<tr>
<td>67</td>
<td>Whitlach et al. (1991)</td>
<td>Carers (113)</td>
<td>Dementia</td>
<td>Reanalysis of data from earlier study (see study no. 95) using prediction analysis</td>
<td>Individual and family counselling. Comparator: support group</td>
<td>8 sessions</td>
<td>Standard outcome measures: carer stress; burden; managing problem behaviour</td>
<td>USA</td>
</tr>
<tr>
<td>Study number</td>
<td>Author(s)</td>
<td>Sample</td>
<td>Care recipient group</td>
<td>Research methods</td>
<td>Intervention</td>
<td>Duration of intervention</td>
<td>Outcomes</td>
<td>Setting</td>
</tr>
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<tr>
<td>74</td>
<td>Szmukler et al. (1996)</td>
<td>Carers (63). Study group (32); control group (31)</td>
<td>Schizophrenia/schizoaffective psychosis</td>
<td>Quantitative. Randomised treatment/control trial. Pre-/post-tests. Follow-up (6 months)</td>
<td>Individual family counselling programme</td>
<td>6 weekly one-hour sessions</td>
<td>Standard outcome measures: carer physical and mental health; appraisal of caring; coping</td>
<td>Australia</td>
</tr>
<tr>
<td>249</td>
<td>Roberts (1999)</td>
<td>Carers (77); study (38); control (39)</td>
<td>Cognitively impaired</td>
<td>Quantitative. Randomised treatment/control trial pre-/post-test. Follow-up (6 and 12 months)</td>
<td>Individualised problem-solving counselling by nurses</td>
<td>10 sessions</td>
<td>Standard outcome measures: psychosocial adjustment to illness; carer burden; social support; coping; use of health and social services</td>
<td>Canada</td>
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</table>
**Table 11  Telephone and computer-based services (N = 16)**

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<th>Study number</th>
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<th>Intervention</th>
<th>Duration of intervention</th>
<th>Outcomes</th>
<th>Setting</th>
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<tbody>
<tr>
<td>25</td>
<td>Goodman (1990)</td>
<td>Carers (40). Network-lecture sequence (22); lecture-network sequence (18)</td>
<td>Alzheimer’s disease</td>
<td>Quantitative. Random assignment. No control group. Pre-/post-tests</td>
<td>Care-Line: model self-help telephone</td>
<td>12 weeks</td>
<td>Standard outcome measures: problem behaviours; burden; mental health; knowledge; satisfaction with supports for caring; social support; family and friend support</td>
<td>USA</td>
</tr>
<tr>
<td>26</td>
<td>Brennan (1993)</td>
<td>Carers (96). Study group (47); control group (49)</td>
<td>Alzheimer’s disease</td>
<td>Quantitative. Randomised controlled trial. Pre-/post-tests</td>
<td>ComputerLink (specialised computer network)</td>
<td>12 months</td>
<td>Standard outcome measures: social isolation, depression, caregiving strain, health status, social well-being, social roles. Service utilisation</td>
<td>USA</td>
</tr>
<tr>
<td>38</td>
<td>Coyne (1991)</td>
<td>Carer respondents (104)</td>
<td>Alzheimer’s disease and other dementias</td>
<td>Quantitative. No control. Post-tests</td>
<td>Statewide toll-free telephone help-line specialising in AD and related dementias</td>
<td>Varied</td>
<td>Specially developed questionnaire; usage patterns; relationship with patient; health status; access to information about services</td>
<td>USA</td>
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</tbody>
</table>
Table 11 Telephone and computer-based services (continued)

<table>
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<tr>
<th>Study number</th>
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<th>Sample</th>
<th>Care recipient group</th>
<th>Research methods</th>
<th>Intervention</th>
<th>Duration of intervention</th>
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<tbody>
<tr>
<td>62</td>
<td>Goodman and Pynoos (1990)</td>
<td>Carers (66); Network component (31); lecture component (35)</td>
<td>Alzheimer’s disease</td>
<td>Quantitative. Random assignment. No control group. Pre-/post-tests</td>
<td>Care-Line: model self-help telephone</td>
<td>12 weeks</td>
<td>Standard outcome measures: problem behaviours; burden; mental health; knowledge; satisfaction with supports for caring; social support; family and friends support</td>
<td>USA</td>
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<tr>
<td>63</td>
<td>Davis (1998)</td>
<td>Carers (17)</td>
<td>Dementia (mild to severe)</td>
<td>Quantitative. No control. Pre-/post-tests</td>
<td>Telephone-based support and skill training</td>
<td>12 weeks</td>
<td>Standard outcome measures: behavioural problems; problem-solving; social support; depression; life satisfaction</td>
<td>USA</td>
</tr>
<tr>
<td>94</td>
<td>Bass et al. (1998)</td>
<td>Carers (96): study group (47); control group (49)</td>
<td>Alzheimer’s disease</td>
<td>Quantitative. Randomised controlled trial. Pre-/post-tests</td>
<td>ComputerLink (specialised computer network)</td>
<td>12 months</td>
<td>Standard outcome measures: carer strain (physical, emotional, relationship, activity restriction), ComputerLine usage</td>
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</table>
Table 11  Telephone and computer-based services (continued)

<table>
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<tr>
<th>Study number</th>
<th>Author(s)</th>
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<th>Research methods</th>
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<th>Duration of intervention</th>
<th>Outcomes</th>
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</thead>
<tbody>
<tr>
<td>97</td>
<td>Brennan (1993)</td>
<td>Persons living with AIDS (51); study group (25); control group (26). Alzheimer's disease (96); study group (47); control group = 49</td>
<td>AIDS; Alzheimer’s disease</td>
<td>Quantitative. Randomised controlled trial. Pre/post-tests</td>
<td>ComputerLink (specialised computer network)</td>
<td>PwA: 6 months. Alzheimer’s disease carers: 12 months</td>
<td>Use patterns</td>
<td>USA</td>
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</table>
Table 11  Telephone and computer-based services (continued)

<table>
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<th>Study number</th>
<th>Author(s)</th>
<th>Sample</th>
<th>Care recipient group</th>
<th>Research methods</th>
<th>Intervention</th>
<th>Duration of intervention</th>
<th>Outcomes</th>
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<tr>
<td>170</td>
<td>White and Dorman (2000)</td>
<td>Messages to mailgroup (532)</td>
<td>Alzheimer’s disease</td>
<td>Content analysis.</td>
<td>Internet Alzheimer Mailgroup</td>
<td>20 days</td>
<td>Content and themes of messages posted on a mailgroup</td>
<td>USA</td>
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<tr>
<td>242</td>
<td>Payton et al. (1995)</td>
<td>Carers (96). Study group (47); control group (49)</td>
<td>Alzheimer’s disease</td>
<td>Quantitative. Randomised controlled trial. Pre-/post-tests</td>
<td>ComputerLink (specialised computer network)</td>
<td>12 months</td>
<td>Institutionalisatio n rate</td>
<td>USA</td>
</tr>
</tbody>
</table>
### Table 11  Telephone and computer-based services (continued)

<table>
<thead>
<tr>
<th>Study number</th>
<th>Author(s)</th>
<th>Sample</th>
<th>Care recipient group</th>
<th>Research methods</th>
<th>Intervention</th>
<th>Duration of intervention</th>
<th>Outcomes</th>
<th>Setting</th>
</tr>
</thead>
<tbody>
<tr>
<td>288</td>
<td>Brennan <em>et al.</em> (1995)</td>
<td>Carers (96). Study group (47); control group (49)</td>
<td>Alzheimer’s Disease</td>
<td>Quantitative. Randomised controlled trial. Pre-/post-tests</td>
<td>ComputerLink (specialised computer network)</td>
<td>12 months</td>
<td>Standard outcome measures: decision-making confidence and skill; social support; burden; depression; carer contact with services</td>
<td>USA</td>
</tr>
</tbody>
</table>
### Table 12 Domiciliary care services (N = 4)

<table>
<thead>
<tr>
<th>Study number</th>
<th>Author(s)</th>
<th>Sample</th>
<th>Care recipient group</th>
<th>Research methods</th>
<th>Intervention</th>
<th>Duration of intervention</th>
<th>Outcomes</th>
<th>Setting</th>
</tr>
</thead>
<tbody>
<tr>
<td>124</td>
<td>Vernooij-Dassen et al. (2000)</td>
<td>Patient-carer pairs (49)</td>
<td>Alzheimer’s disease or related dementia</td>
<td>Secondary data analysis of earlier randomised control trial</td>
<td>Support Programme provided by home helps</td>
<td>4 hours/week for 10 months</td>
<td>Standard outcome measures: sense of competence; neuroticism; social support; Number of patient admissions to institutional care</td>
<td>Netherlands</td>
</tr>
<tr>
<td>283</td>
<td>Whitby et al. (1999)</td>
<td>Not given</td>
<td>Elderly confused</td>
<td>Quantitative. No control. Post-test only</td>
<td>Support and Stay (SaS) community service</td>
<td>Not clear</td>
<td>Survey: carers’ perceptions of ability of continue to care without the SaS service</td>
<td>UK</td>
</tr>
</tbody>
</table>
## Table 13  Physical Environment (N = 3)

<table>
<thead>
<tr>
<th>Study number</th>
<th>Author(s)</th>
<th>Sample</th>
<th>Care recipient group</th>
<th>Research methods</th>
<th>Intervention</th>
<th>Duration of intervention</th>
<th>Outcomes</th>
<th>Setting</th>
</tr>
</thead>
<tbody>
<tr>
<td>183</td>
<td>Gitlin et al. (2001)</td>
<td>Carers (171); Study (93); control (78)</td>
<td>Dementia</td>
<td>Quantitative. Randomised control led trial. Baseline; Follow-up (3 months)</td>
<td>Home environmental intervention</td>
<td>5 90-minute home visits over 3 months</td>
<td>Standard outcome measures: carer well-being (self-efficacy and upset in managing dementia behaviours)</td>
<td>USA</td>
</tr>
<tr>
<td>187</td>
<td>Corcoran and Gitlin (1992)</td>
<td>Case example of one carer</td>
<td>Dementia</td>
<td>Case vignette of one carer</td>
<td>Home-based occupational therapy/environmental intervention</td>
<td>5 90-minute home visits over 3 months</td>
<td>Developing and implementing effective environmental strategies</td>
<td>USA</td>
</tr>
</tbody>
</table>
**Table 14 Supporting Carers through Memory Clinics (N = 2)**

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

<table>
<thead>
<tr>
<th>Study number</th>
<th>Author(s)</th>
<th>Sample</th>
<th>Care recipient group</th>
<th>Research methods</th>
<th>Intervention</th>
<th>Duration of intervention</th>
<th>Outcomes</th>
<th>Setting</th>
</tr>
</thead>
<tbody>
<tr>
<td>29</td>
<td>Mohide et al. (1990)</td>
<td>Carer–patient dyads (60 pairs). Study group (30 pairs); control group (30 pairs)</td>
<td>Dementia: moderate–severe</td>
<td>Quantitative. Randomised controlled trial. Pre-/post-tests. Follow-up (12-18 months)</td>
<td>Carergiver Support Programme</td>
<td>6 months</td>
<td>Standard outcome measures: burden; depression; anxiety; quality of life; health; impact of caring</td>
<td>Canada</td>
</tr>
<tr>
<td>41</td>
<td>Pritchard and Dewing (2001)</td>
<td>Interviews: clients (5); carers (5); others(23). Questionnaires: numbers not given</td>
<td>Alzheimer’s disease</td>
<td>Mixed. No control group. Post-test</td>
<td>SPECAL (Specialized Early Care of Alzheimer’s)</td>
<td>Not given</td>
<td>Development of project/services; quality of services/approach; factors for future development</td>
<td>UK</td>
</tr>
<tr>
<td>52</td>
<td>Millan-Calenti et al. (2000)</td>
<td>Carers (14)</td>
<td>Alzheimer’s disease</td>
<td>Quantitative. No control. Pre-/post-tests. Follow-up (12 months)</td>
<td>Support Programme</td>
<td>Not given</td>
<td>Standard outcome measures: physical and mental health; social life; support; burden; anxiety</td>
<td>Spain</td>
</tr>
<tr>
<td>119</td>
<td>Chu et al. (2000)</td>
<td>Client–carer pairs (75 pairs). Study group (37 pairs); control group (38 pairs)</td>
<td>Early-stage Alzheimer’s disease</td>
<td>Quantitative. Control group. Pre-/post-tests</td>
<td>Early Home Care Programme</td>
<td>18 months</td>
<td>Standard outcome measures: burden; disturbing behaviours; depression. Records of service use</td>
<td>Canada</td>
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</tbody>
</table>
Table 15  Multidimensional approaches to caring interventions (continued)

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

<table>
<thead>
<tr>
<th>Study number</th>
<th>Author(s)</th>
<th>Sample</th>
<th>Care recipient group</th>
<th>Research methods</th>
<th>Intervention</th>
<th>Duration of intervention</th>
<th>Outcomes</th>
<th>Setting</th>
</tr>
</thead>
<tbody>
<tr>
<td>176</td>
<td>Fisher and Savin-Baden (2001)</td>
<td>Patients (5); carers/relatives (1); professionals (7)</td>
<td>Schizophrenia or related disorder (16–25 years)</td>
<td>Qualitative. No control. No pre-participation measures. Interviews with all key stakeholder groups</td>
<td>TIME (occupational therapy programme)</td>
<td>6 months</td>
<td>Evaluation of the TIME programme</td>
<td>UK</td>
</tr>
<tr>
<td>203</td>
<td>Drummond et al. (1991)</td>
<td>Carers (60). Study group (30); control group (30)</td>
<td>Dementia (moderate–severe)</td>
<td>Quantitative. Randomised controlled trial. Pre-/post-tests</td>
<td>Caregiver Support Programme (CSP)</td>
<td>6 months</td>
<td>Standard outcome measures: depression; anxiety; quality of life</td>
<td>Canada</td>
</tr>
<tr>
<td>208</td>
<td>Fox et al. (2000)</td>
<td>Clients (8095). Study group (4151); control group (usual care) (3944)</td>
<td>Dementia</td>
<td>Quantitative. Randomised controlled trial. Baseline and five further assessments</td>
<td>MADD (Medicare Alzheimer Disease Demonstration). Two case management models: one high resource, and one low resource</td>
<td>36 months</td>
<td>Standard outcome measures: carer burden; depression</td>
<td>USA</td>
</tr>
<tr>
<td>238</td>
<td>Newcomer et al. (1999a)</td>
<td>Clients (5307). Study group (2731); control group (usual care) (2576)</td>
<td>Dementia</td>
<td>Quantitative. Randomised controlled trial. Baseline and five further assessments</td>
<td>MADD (Medicare Alzheimer Disease Demonstration). Two case management models: one high resource, and one low resource</td>
<td>36 months</td>
<td>Standard outcome measures: carer burden; depression</td>
<td>USA</td>
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</table>
Table 15  Multidimensional approaches to caring interventions (continued)

<table>
<thead>
<tr>
<th>Study number</th>
<th>Author(s)</th>
<th>Sample</th>
<th>Care recipient group</th>
<th>Research methods</th>
<th>Intervention</th>
<th>Duration of intervention</th>
<th>Outcomes</th>
<th>Setting</th>
</tr>
</thead>
<tbody>
<tr>
<td>239</td>
<td>Newbronner et al. (1999b)</td>
<td>Clients (8,095). Study group (4151); control group (usual care) (3944)</td>
<td>Dementia</td>
<td>Quantitative. Randomised controlled trial. Baseline and five further assessments</td>
<td>MADD (Medicare Alzheimer Disease Demonstration). Two case management models: one high resource, and one low resource</td>
<td>36 months</td>
<td>Standard outcome measures: carer burden; depression. Medicare claims records</td>
<td>USA</td>
</tr>
<tr>
<td>267</td>
<td>Weinberger et al. (1993b)</td>
<td>Carers (264). Study group (193); control group (71)</td>
<td>Progressive memory disorders</td>
<td>Quantitative. Randomised controlled trial. Pre-/post-tests</td>
<td>Individualised service plans (designed to enhance compliance)</td>
<td>6 months</td>
<td>Standard outcome measures: health services utilisation and expenditures</td>
<td>USA</td>
</tr>
<tr>
<td>268</td>
<td>Wenger et al. (2000)</td>
<td>Patients and carers (50 pairs). Study group (27 pairs); control group (23 pairs)</td>
<td>Dementia</td>
<td>Mixed. Matched controls. Pre-/post-tests</td>
<td>Early intervention, including specialist input by 'Dementia Care Specialist'</td>
<td>15 months</td>
<td>Standard outcome measures: support network; loneliness and isolation; difficulties; satisfactions; managing/coping; psychological distress; anxiety; depression</td>
<td>UK</td>
</tr>
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</table>
Table 16 Miscellaneous (N = 8)

<table>
<thead>
<tr>
<th>Study number</th>
<th>Author(s)</th>
<th>Sample</th>
<th>Care recipient group</th>
<th>Research methods</th>
<th>Intervention</th>
<th>Duration of intervention</th>
<th>Outcomes</th>
<th>Setting</th>
</tr>
</thead>
<tbody>
<tr>
<td>27</td>
<td>Quayhagen et al. (2000)</td>
<td>Carer–patient dyads (103). Cognitive stimulation group (21); dyadic counselling group (29); dual seminar group (22); early day care group (16); control group (15)</td>
<td>Dementia: mild–moderate</td>
<td>Quantitative. Control group. Pre-/post-tests</td>
<td>One of four treatment programmes: cognitive stimulation; dyadic counseling; dual supportive seminar; early-stage day care</td>
<td>8 weeks</td>
<td>Standard outcome measures: marital interaction, emotional status, physical health, stress, coping and social support. Programme evaluation questionnaire</td>
<td>USA</td>
</tr>
<tr>
<td>28</td>
<td>Cohen et al. (1998)</td>
<td>Carers (7)</td>
<td>Dementia</td>
<td>Mixed. No control group. Pre-/post-tests</td>
<td>Network therapy</td>
<td>Not clear</td>
<td>Standard outcome measures: social support; burden</td>
<td>Canada</td>
</tr>
<tr>
<td>163</td>
<td>Simpson (1997)</td>
<td>Carers (20); Community Mental Health Team professionals</td>
<td>Dementia</td>
<td>Mixed. No control. Post-tests</td>
<td>Carer-held record documentation</td>
<td>6 months</td>
<td>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</td>
<td>UK</td>
</tr>
</tbody>
</table>
## Table 16 Miscellaneous (continued)

<table>
<thead>
<tr>
<th>Study number</th>
<th>Author(s)</th>
<th>Sample</th>
<th>Care recipient group</th>
<th>Research methods</th>
<th>Intervention</th>
<th>Duration of intervention</th>
<th>Outcomes</th>
<th>Setting</th>
</tr>
</thead>
<tbody>
<tr>
<td>166</td>
<td>Perodeau et al. (2001)</td>
<td>Carers (194), Drug users (61), Non-users (133)</td>
<td>Dementia</td>
<td>Secondary data analysis of earlier study. Quantitative. Control group. Post-test only</td>
<td>Psychotropic drug use</td>
<td>Varied</td>
<td>Standard outcome measures: psychotropic drug-use; psychological distress; dysfunctional behaviours; conflicts in interpersonal relationships; coping strategies; social support; health status</td>
<td>Canada</td>
</tr>
<tr>
<td>167</td>
<td>Winslow (1998)</td>
<td>Carer (1); service providers (2)</td>
<td>Alzheimer’s disease</td>
<td>Qualitative. Case study approach. Post-test only</td>
<td>Formal community support services</td>
<td>18 months</td>
<td>In-depth interviews; observations: carer’s experiences of services</td>
<td>USA</td>
</tr>
<tr>
<td>177</td>
<td>Aimonino et al. (2001)</td>
<td>Patients (82), HHS (41), GMW (41), Carers (numbers not given)</td>
<td>Dementia: advanced</td>
<td>Quantitative. No control. Tests at admission and discharge</td>
<td>Home Hospitalisation Service (HHS). Comparator: patients in a general medical ward (GMW)</td>
<td>Varied</td>
<td>Standard outcome measures: stress</td>
<td>Italy</td>
</tr>
<tr>
<td>232</td>
<td>Knapp et al. (1998)</td>
<td>Patients (189), DLP (92); control (97)</td>
<td>Severe mental illness</td>
<td>Quantitative. Randomised controlled trial. Pre-/post-tests. Follow-up (4 years)</td>
<td>Daily Living Programme (DLP) for 45 months. Comparators: DLP (20 months) plus standard care (25 months); standard care (45 months)</td>
<td>Varied</td>
<td>Standard outcome measures: social. Patients’ and relatives’ satisfaction</td>
<td>UK</td>
</tr>
<tr>
<td>Study number</td>
<td>Author(s)</td>
<td>Sample</td>
<td>Care recipient group</td>
<td>Research methods</td>
<td>Intervention</td>
<td>Duration of intervention</td>
<td>Outcomes</td>
<td>Setting</td>
</tr>
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<tr>
<td>250</td>
<td>Rudolph <em>et al.</em> (1998)</td>
<td>Patients (76); carers (32)</td>
<td>Mental retardation</td>
<td>Quantitative. Longitudinal study with hypothetical controls</td>
<td>Behavioural support and crisis response</td>
<td>Varied</td>
<td>Care-provider and case manager satisfaction levels</td>
<td>USA</td>
</tr>
</tbody>
</table>
Appendix 5

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

<table>
<thead>
<tr>
<th>Study number</th>
<th>Author(s)</th>
<th>Intervention category group</th>
<th>Sample</th>
<th>Care recipient group</th>
<th>Research methods</th>
<th>Intervention</th>
<th>Duration of intervention</th>
<th>Outcomes</th>
<th>Setting (currency)</th>
</tr>
</thead>
<tbody>
<tr>
<td>200</td>
<td>Creed (1997)</td>
<td>Breaks from caring – ADC</td>
<td>89 inpatients (52 carers); 90 day patients (51 carers)</td>
<td>Acute psychiatric illness</td>
<td>Quantitative. Randomised control trial. Pre-tests; regular follow-up (up to 12 months)</td>
<td>Day hospital vs. routine inpatient care for persons with acute psychiatric illness</td>
<td>Varied</td>
<td>Standard outcome measures: carer distress. Cost - effectiveness</td>
<td>UK hospital (£)</td>
</tr>
<tr>
<td>201</td>
<td>Donaldson (1989)</td>
<td>Breaks from caring – mixed respite</td>
<td>EMI patients (105); 35 intervention (24 carers); 70 controls (29 carers)</td>
<td>Elderly mentally infirm (EMI)</td>
<td>Quantitative. Case series with matched controls. Pre-/post-tests</td>
<td>Family support unit (co-ordinated and flexible community care)</td>
<td>Varied</td>
<td>Costs, benefits and effects of providing care for carers</td>
<td>UK (Scotland) community (£)</td>
</tr>
<tr>
<td>203</td>
<td>Drummond (1991)</td>
<td>Multidimensional</td>
<td>Carers (60). Study group (30); control group (30)</td>
<td>Dementia (moderate – severe)</td>
<td>Quantitative. Randomised controlled trial. Pre-/post-tests</td>
<td>Caregiver Support Programme (CSP)</td>
<td>6 months</td>
<td>Standard outcome measures: depression; anxiety; quality of life</td>
<td>Canada community (CANS$)</td>
</tr>
</tbody>
</table>
Summary of findings from the economic literature (continued)

<table>
<thead>
<tr>
<th>Study number</th>
<th>Author(s)</th>
<th>Intervention category group</th>
<th>Sample</th>
<th>Care recipient group</th>
<th>Research methods</th>
<th>Intervention</th>
<th>Duration of intervention</th>
<th>Outcomes</th>
<th>Setting (currency)</th>
</tr>
</thead>
<tbody>
<tr>
<td>208</td>
<td>Fox (2000)</td>
<td>Multidimensional</td>
<td>Clients (8095) Study group (4151); control group (usual care) (3944)</td>
<td>Dementia</td>
<td>Quantitative. Randomised controlled trial. Baseline and five further assessments</td>
<td>MADD (Medicare Alzheimer Disease Demonstration). Two case management models: one high resource, and one low resource</td>
<td>36 months</td>
<td>Standard outcome measures; carer burden; depression</td>
<td>US community (US$)</td>
</tr>
<tr>
<td>208</td>
<td>Fox (2000)</td>
<td>Multidimensional</td>
<td>Clients (8095) Study group (4151); control group (usual care) (3944)</td>
<td>Dementia</td>
<td>Quantitative. Randomised controlled trial. Baseline and five further assessments</td>
<td>MADD (Medicare Alzheimer Disease Demonstration). Two case management models: one high resource, and one low resource</td>
<td>36 months</td>
<td>Standard outcome measures; carer burden; depression</td>
<td>US community (US$)</td>
</tr>
<tr>
<td>232</td>
<td>Knapp (1998)</td>
<td>Miscellaneous</td>
<td>Patients (189). DLP (92); control (97)</td>
<td>Sever mental illness</td>
<td>Quantitative. Randomised controlled trial. Pre-/post-tests. Follow-up (4 years)</td>
<td>Daily Living Programme (DLP) for 45 months. Comparators: DLP (20 months) plus standard care (25 months); standard care (45 months)</td>
<td>Varied</td>
<td>Standard outcome measures; social. Patients’ and relatives’ satisfaction</td>
<td>UK community (£)</td>
</tr>
</tbody>
</table>
### Summary of findings from the economic literature (continued)

<table>
<thead>
<tr>
<th>Study number</th>
<th>Author(s)</th>
<th>Intervention category group</th>
<th>Sample</th>
<th>Care recipient group</th>
<th>Research methods</th>
<th>Intervention</th>
<th>Duration of intervention</th>
<th>Outcomes</th>
<th>Setting (currency)</th>
</tr>
</thead>
<tbody>
<tr>
<td>250</td>
<td>Rudolph (1998)</td>
<td>Miscellaneous</td>
<td>Patients (76), Carers (32)</td>
<td>Mental retardation</td>
<td>Quantitative, Longitudinal study with hypothetical controls</td>
<td>Behavioural support and crisis response</td>
<td>Varied</td>
<td>Care provider and case manager satisfaction levels</td>
<td>US community (US$)</td>
</tr>
<tr>
<td>261</td>
<td>Tarrier (1991)</td>
<td>Family</td>
<td>Carers (73); High EE study group (25); High EE control group (29); Low EE control group (19)</td>
<td>Schizophrenia</td>
<td>Quantitative, Control group. Pre-/post-tests</td>
<td>Nine month family intervention. Comparator: short educational programme or routine care</td>
<td>9 months</td>
<td>Relapse rate in patients</td>
<td>UK community (£)</td>
</tr>
<tr>
<td>263</td>
<td>Van Minnen (1997)</td>
<td>Family</td>
<td>Patients (50); Outreach treatment (25); Hospital care/control (25)</td>
<td>Serious mental illness</td>
<td>Quantitative, Randomised controlled trial. Pre-/post-tests</td>
<td>Outreach treatment. Comparator: hospital care</td>
<td>28 weeks</td>
<td>Standard outcome measures: family burden. Hospital admissions</td>
<td>Netherlands mixed (US$)</td>
</tr>
</tbody>
</table>
## Summary of findings from the economic literature (continued)

<table>
<thead>
<tr>
<th>Study number</th>
<th>Author(s)</th>
<th>Intervention category group</th>
<th>Sample</th>
<th>Care recipient group</th>
<th>Research methods</th>
<th>Intervention</th>
<th>Duration of intervention</th>
<th>Outcomes</th>
<th>Setting (currency)</th>
</tr>
</thead>
<tbody>
<tr>
<td>268</td>
<td>Wenger (2000)</td>
<td>Multidimensional</td>
<td>Patients and carers (50 pairs). Study group (27 pairs); control group (23 pairs)</td>
<td>Dementia</td>
<td>Mixed. Matched controls. Pre-/post-tests</td>
<td>Early intervention, including specialist input by 'Dementia Care Specialist'</td>
<td>15 months</td>
<td>Standard outcome measures: support network; loneliness and isolation; difficulties; satisfactions; managing/coping; psychological distress; anxiety; depression</td>
<td>UK community (£)</td>
</tr>
</tbody>
</table>
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