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Access to Health Care for Carers: Intervention Evaluations

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

December 2003

prepared by

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Section 1 Introduction

This document supplements the main report of the findings of new research examining barriers to carers' access to health care, and interventions to improve accessibility (Arksey *et al.*, 2003). The study involved a review of the literature and a consultation with key stakeholder groups; full information about the methods adopted are contained in Chapter 2 of the main report. Chapter 4 of that report examines the effectiveness of 14 interventions designed to improve carers' access to health care. The work contained in the present document comprises detailed information about the interventions, material that we were unable to include in the main report because of space restrictions.

For the purposes of the review, the 14 evaluation reports were divided into two groups, core and intermediate studies, based on strength of evidence. Table 1.1, showing the nine core evaluation studies, comprises those studies that present the best evidence. The research is of good quality and includes data with direct relevance to the issues relating to access to health care for carers. These nine core studies present a mix of B-type evidence according to the typology of study designs (see Appendix 1) used to categorise all 46 studies included in the review (32 of the 46 studies presented evidence about barriers to access, and were the subject of Chapter 3 of the main report).

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Table 1.1 Core evaluation studies (n=9)

ID number	Author(s)	Intervention and main aims	Research design and study typology design code
33	Naish and Benaim (1995)	*Hackney and Newham GP–Carers Project* To improve support to carers	Mixed methods B3
36	Stevens (1999)	*Paignton and Brixham GP Carers Project* To identify and support carers; to promote carer awareness	Mixed methods B3
38	Morris (2002)	*Brent Primary Care Project* To provide carers with one-to-one advice, support and training; to develop awareness of carers' issues in GP practices	Mixed methods B3
39	Brown *et al.* (1999)	*Telephone Carer Groups* To compare the impact of telephone carer groups with traditional carer groups	Quantitative methods B2
40*	Gallienne *et al.* * (1993)	*ComputerLink* To provide support to carers of people with Alzheimer's disease via ComputerLink	Quantitative methods B1
41	Magnusson *et al.* (2002)	*Telematic Inverventions* To provide direct support and information to carers and care recipients via computer technology	Mixed methods B3
43	Mahoney (2001)	*Telephone linked care* To help carers of people with Alzheimer's disease with advice and access to a support group via the telephone	Quantitative methods B1
45	John (2000)	*Mobile Therapy Unit* To relieve symptoms of stress in carers and people with dementia	Quantitative methods B2
46	Foley (2002)	*Geographical Information Systems* (GIS) To assess the potential applicability of GIS software through a study of carers and the provision of short term breaks	Mixed methods B3

* Exceptionally, our evidence about ComputerLink also draws on a further three related articles, which included more detailed information about methodology, strengths and weaknesses of the system (Brennan *et al.*, 1991; Brennan *et al.*, 1992; Bass *et al.*, 1998).

Table 1.2 shows the five intermediate studies, presenting C-type evidence. These studies address the central issue of carers' access to health care to a lesser extent, and/or their quality is less robust than the core studies.

Table 1.2 Intermediate evaluation studies (n=5)

ID number	Author(s)	Intervention and aim	Research design and study typology design code
34	Lloyd (1996)	*Newhaven Carers Project* To promote and protect the health of carers	Qualitative methods C1
35	Tarry (1998)	*Carers Primary Care* Project at Fairfield Surgery, Burwash To identify and assist carers	Qualitative methods C1
37	Morris (2000)	*Cornwall Carer Support Workers Service* To improve support for carers offered by primary health care practitioners	Quantitative methods C1
42	Lazarus (1998)	*Relaxation distance learning audiotape* To reduce carers' stress levels	Quantitative methods C1
44	MacDonald (1998)	*Massage for primary carers* To reduce carers' stress and fatigue	Quantitative methods C1

For the purposes of the present report, we identify individual evidence categories in the heading for each intervention discussed below in order to indicate the strength of evidence. We also make passing reference to a number of guidelines and toolkits that have been published recently, some of which have a stronger evidence base than others, but again we identify this on an individual basis. A summary table giving more details about all the studies included in each of the three groups can be found in Appendix 2

For the convenience of readers, it is worth explaining that the main report used as its organising principle a typology of barriers to access to health care specifically faced by carers. The typology contained five different types of barriers relating to:

- professional characteristics;
- service issues;
- language or cultural issues;
- carer or care recipient characteristics;
- information and knowledge issues.

Box 1.1 provides examples of discrete barriers to help illustrate different types of 'barriers-within-a-barrier' covered under each 'umbrella' heading.

Box 1.1 Typology of barriers to access to health care for carers

Professional characteristics

professionals' personal characteristics; professional awareness of carers; professionals' approach and attitudes towards carers.

Service issues

appointment systems; waiting lists, admission criteria; follow-up; staffing; agency policies and practices; eligibility criteria; identification systems for recording patients who are carers; costs/charges; proximity; transport; physical environment of service premises; parking facilities.

Language or cultural issues: language differences

cultural beliefs and preferences; appropriateness of services in terms of cultural, religious and language needs; racial prejudice and discrimination.

Carer or care recipient characteristic

help-seeking behaviour; individual preferences; perceptions of quality of care; perceptions of need; financial resources; anxiety; previous experience; community and family support; perceived availability of services; willingness and interest in obtaining services.

Information and knowledge issues

information about, and knowledge of, available services and procedures; medical confidentiality issues.

The approach we have taken in writing up this supplementary report has been to try to answer the question: how or why does this intervention work, and for whom? In other words, rather than just discuss the outcomes of interventions we instead report on a range of factors, including the context or processes that feed into the final outcomes. We also indicate which groups of carers appear to have the most – or least – to gain from the different types of interventions, where this information was available in the primary report. To this end, we discuss the interventions individually within each of the three groups and under the standard headings, as follows:

- Description of intervention
- Barriers addressed
- Evaluation
- Outcomes
- Strengths of the structure, process and outcomes of the intervention
- Weakness of the structure, process and outcomes of the intervention
- Key learning points.

The reminder of the report is organised as follows. The next section focuses on primary care initiatives, which leads in Section 3 into a brief overview of recently published guidelines and 'toolkits' to help professionals improve their support for carers. Sections 4 and 5 look at home-based health projects and

GIS software respectively. The concluding section, Section 6, draws on the evidence to suggest which groups of carers are likely to benefit (or not, as the case may be) from the different types of intervention.

Section 2 Primary care initiatives

2.1 Hackney and Newham GP–Carers Project (ID number 33; evidence category B3)

Description of intervention

The Hackney and Newham GP–Carers Project was a developmental project to work with GPs in the two boroughs between September 1992 and January 1995. It was funded by the King's Fund Centre, and supported by the City & East London Family Health Service Authority (FHSA). The overall aims of the project were to improve the amount and quality of support carers received through general practice, and to develop in practice terms the concept of 'partnership' between general practice and carers, paying particular attention to achieving recognition of carers' expertise and skills. The project's supervisor was a Newham GP and senior lecturer in the Department of General Practice and Primary Care at the Medical College of St Bartholomew's and the London Hospitals. Two part-time project development workers were appointed to work with general practices, one in Hackney and one in Newham. A steering group was established and met two-monthly.

The project comprised projects-within-the-project. First of all, pilot projects were initiated in two GP practices in Hackney. One was concerned with an information resource, and the second focused on practice procedures to identify and support carers. Final project work in Hackney involved working in three practices focusing on respectively: a health check system for carers of elderly mentally ill patients; a survey of one practice's carers about the services offered; the role of receptionists as information givers to carers. For a variety of reasons, no pilot projects were established in Newham. Final project work in that borough comprised a series of six workshops with educational aims. These were attended by practice nurses, practice managers and receptionists from 13 practices, as well as representatives from social services and carers' organisations. No specific project was initiated targeting support for carers from ethnic minority communities.

Clearly, the Hackney and Newham GP–Carers Project was wide ranging. It is not possible within the constraints of this report to discuss all aspects of all the individual projects. However, one of the Hackney final projects – the health check system for carers – was particularly relevant and novel from the point of view of the present review. The 'Outcomes', 'Strengths' and 'Weaknesses' paragraphs below concentrate on issues related to that specific project. The other paragraphs, however, relate to the overall project.

Barriers addressed

Professional characteristics; service issues; carer or care recipient characteristics; information and knowledge issues. Specific objectives with the potential to improve carers' access to health care included: developing and

monitoring proactive interventions for carers to improve their physical and mental health; providing carer awareness training to primary care team members; developing procedures to identify carers; providing information about local services and how to access them.

Evaluation

The evaluation was led by the Department of General Practice. Different methods were adopted as appropriate for the different projects. These involved finding out the views of carers, GPs and other members of the primary care team either through face-to-face interviews or questionnaire surveys.

Outcomes

The health check system for carers project aimed to investigate levels of interest of carers of elderly mentally ill people in a special 'carer health check appointment' at which their health, caring situation and concerns about the person they were caring for could be addressed. Some 11 carers met the project worker, seven of whom took up the option of a special carer appointment with the GP. The appointment comprised basic health checks (checking weight, blood pressure, review of own general health), and then an opportunity to discuss concerns about the carer's own health and that of the person cared for. Analysis of evaluation questionnaires sent to carers showed that they believed the appointment system was beneficial; in particular they were encouraged by being recognised as carers and felt reassured by the practice's commitment to monitor their ability to continue caring. At the practical level, referrals for community care assessments and respite care were made immediately. The GP practice piloting the services was keen to retain it; the likelihood was that it would be offered on an annual basis conducted one year by a GP and the following year by a practice nurse.

Strengths of the structure, process and outcomes of the intervention

The practice staff felt that having special appointments for carers meant they could monitor situations that were often vulnerable and prone to break down. The intention to try to review carers in a 'batch' annually potentially meant that staff's efforts would be focused on carers over a short period of time. In principle, being more attuned to carers over a short period would enable staff to deal more efficiently with their individual and group needs. The practice had a system of tagging those patients who were carers on their computerised notes, which would facilitate identifying (new) patients who became carers of elderly mentally ill patients and then adding their names to the list of those offered a special carer appointment. Information derived from the annual special appointments could then be appropriately shared within the regular practice clinical meetings so that relevant staff (such as district nurses) were made aware of the carer's situation and could contribute to the care arrangements, if necessary.

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Weaknesses of the structure, process and outcomes of the intervention

The innovation highlighted the need for good and efficient links with social services, which the practice intended to forge in the future.

Key learning points

(from all five projects established under the Hackney and Newham GP–Carers Project)

- Carer support project work needs to be individually tailored to the specific practice in question, acknowledging its own particular culture and organisation.
- The assent of the partners of the practice is important, even if much of the project work will be done with administrative or nursing staff.
- To achieve change, think about starting 'small' and aim for what is achievable. The reality is that it is not possible to suggest massive large-scale changes to organisations that in practical terms do not have the capacity to engage in them.
- Practices need effective systems for identifying carers, and a designated member of staff to maintain them, in order to support carers.
- Time to set up new systems and good practice for carers is difficult to create in GP practices functioning as 'businesses'.
- Where carers are not on the same general practice register as the person they support, communication between professionals becomes complicated and cumbersome, and issues of confidentiality have the potential to cause real problems.
- It is important to address issues relating to the sustainability of new systems and procedures if development work initiated by project workers over a fixed time scale is to be continued. A related issue is that of keeping information packs and local directories of services up to date.
- While spreading good practice is important and can be done through established forums, finding time to release people for meetings can be difficult.
- There are training implications, not only for new staff but also to update existing staff.
- Success is dependent on the support of a variety of local organisations, who can be involved through representation on a steering group.
- If extra support is needed from social services, that may be forthcoming if better links are forged.

2.2 Newhaven Carers Project (ID number 34; evidence category C1)

Description of intervention

The Newhaven Carers Project was designed as a pilot project to work, for one year, with primary care teams to promote and protect the health of patients who were carers. Funding of approximately £10,000 from the FHSA and East Sussex Health Authority was used to employ a part-time (15 hours per week) carers support worker to work in two GP practices based in the Newhaven Health Centre (and certain Peacehaven practices) from June 1995 to May 1996.

Barriers addressed

Professional characteristics; service issues; carer or care recipient characteristics; information and knowledge issues. Specific objectives with the potential to improve carers' access to health care included: providing carer awareness training to all members of the primary care team; creating procedures to identify carers; offering support to carers through the development of appropriate primary care services; promoting the provision of local information.

Evaluation

An independent evaluation of the project was undertaken by the University of Sussex. The evaluation was based on interviews with key stakeholders, and attendance at steering committee meetings. It was concluded that the Newhaven Carers Project was successful in achieving most of its aims. However, it was noted that while the benefits to carers can be assumed, they cannot be accurately measured. The report's author pointed out that the receipt of attendance allowance, joining a support group or receiving information about the latest technology does not provide information about the extent to which this has improved the carer's quality of life or prevented the onset of their own acute illness.

Outcomes

Procedures were developed whereby carers were identified and a logo attached to their paper notes; one practice identified carers on computerised notes. Over 200 carers were identified, mainly by the practice staff. A very small number were identified by GP referrals, and slightly more by self-referral. Identified carers were then followed up by the carers support worker to ascertain what help might be given. An information pack was produced, detailing support services and facilities, to be distributed on request. A monthly carers support group was established; a number of carers received counselling and advocacy services (often in relation to completing claim forms for attendance allowance).

Strengths of the structure, process and outcomes of the intervention

Both GPs and practice staff agreed that the new procedures devised by the project did not seem to have greatly increased their workload. In principle, it was feasible that the practice staff and other professionals could maintain these procedures without too much difficulty. Only time would tell, however, whether routine carer identification and support would become a self-sustaining process.

Weaknesses of the structure, process and outcomes of the intervention

There were considerable changes within health, Social Services and FHSA organisations while the project was taking place, which led to changes and lapses among membership of the steering committee. The lack of involvement by Social Services might have resulted in the subsequent lack of input, through referrals for instance, by other Social Services staff.

Some events took a long time to organise, for example training sessions for GPs and staff which might have been seen as a necessary preliminary to the project were not held until eight months after the project began.

Newhaven Health Centre was overcrowded, and the support worker's room was at the back of the building; this location rendered the project invisible rather than visible, and inhibited casual discussions with health professionals. A separate, direct telephone line meant that closer contact by the carer support worker with other staff was lost.

It was difficult for the carers support worker to make demands on other people's time before it was clear that the result of the end product was worthwhile, but she needed their support in order to establish these benefits. Several GPs gave considerable support to the project, while others seemed to express little concern.

Key learning points

- The carer support worker should be provided with a highly visible office within the practice premises, complete with computer and telephone.
- Identification of carers is difficult, and identification processes may raise ethical and confidentiality concerns.
- All new patients, and all over-75s at their annual screening, should be asked about possible caring roles.
- Once identified, the anonymity and privacy of carers must be preserved; carers must proactively request help.
- Training in carer awareness for GPs and other members of primary care teams is critical.
- GP practices should hold information about local and national carer support facilities which is kept up to date by a nominated member of the practice staff.

- It might be useful for project workers to visit other similar projects to learn from their experiences and relate them to the local situation.
- For a project to succeed, it must maintain a high profile and win the active support of all.

2.3 Carers Primary Care Project at Fairfield Surgery, Burwash
(ID number 35; evidence category C1)

Description of intervention

The project brief was to identify and then help in any way possible carers on the list of two GPs at the Fairfield Surgery in Burwash, East Sussex. The project was funded by the National Lottery, and comprised 15 hours of a worker's time, weekly, over a two-year period. It began in July 1996. A room at the surgery was made available for two half-days per week. The project was actively supported by the health authority which was represented on the steering group together with other statutory and voluntary agencies. A second project on Information began at the same time, under the auspices of the Sussex Rural Community Council. However, this was discontinued after nine months.

Barriers addressed

Professional characteristics; service issues; carer or care recipient characteristics; information and knowledge issues. Specific objectives with the potential to improve carers' access to health care included: offering information to carers; raising the awareness of the practice staff about carers' issues; establishing a carers' support group in the Burwash area; improving the health and financial welfare of carers; improving the provision of local services.

Evaluation

The report of the project was written by the project worker. It included a range of performance or management data to analyse the characteristics of carers and individuals making the referrals, together with comments from both carers and GPs. However, few details are given about how these latter data were collected. Although the evidence base is weaker than we would like, the evaluation does fill a gap in the review in that it focuses on a primary care initiative located in a rural setting.

Outcomes

Some 93 carers were helped by the project, many in relation to welfare benefits. The total sum added to carers' resources by the project was in the order of £30,000 – a gain of almost twice the cost of the project. A support group was established within the project involving monthly meetings at the surgery. Carer awareness in the practice increased. The project funding was sufficient for two years. However, due to reductions in the numbers of

referrals, the project worker put in fewer hours per week and those hours then continued to be used to extend the project. At the time of the evaluation, it was likely that a new worker would be appointed, with funding from the Rural Development Commission Rural Challenge fund, who would include carers from the Burwash project as part of their responsibilities for a larger geographical catchment area.

Strengths of the structure, process and outcomes of the intervention

A pattern of contact was devised that suited the majority of carers. Carers were generally visited in their homes, usually within a week or so of the initial phone call making contact. Agreed action was initiated, and check calls were made after six months. Very few people wished to talk at the surgery.

The district nurse was particularly helpful to the project, and in addition to making referrals helped to run the support group.

The project worker had no problems contacting staff at the surgery, and had good access to the two doctors.

There appeared to be no extra workload placed on any practice staff.

Weaknesses of the structure, process and outcomes of the intervention

Some time had to be spent both initially and over the first few months dealing with technical matters related to the computer and database software. Attending a ten-week course on welfare benefits for one afternoon a week also took time away from dealing directly with carers, but did help considerably in the subsequent work.

The number of carers identified was low; no young carers were found, and the numbers caring for people with psychiatric diagnoses (other than dementia) were small. It was not possible to set up any comprehensive method of screening for carers, as it would have put too much extra work onto other staff for little 'expected' return. The doctors were not able to agree on a system to tag carers' notes and/or computer records.

The majority of referrals came from one particular doctor. While a referral letter had been devised together with the doctors, this was not brought into use, and referrals were made much more informally.

Due to staff shortages and internal reorganisations, Social Services were unable to provide a member of staff to assist with the support group. Again due to staff changes and sickness, no meetings took place of the steering group from November 1997 until the end of the project (June 1998).

Key learning points

- It is important for the project and worker to be acceptable in the surgery setting.
- A professional background helped establish the worker in the initial stages.
- The routine presence of the worker in the surgery facilitated practice staff's confidence in, and knowledge of, the project.
- The introduction of two new projects at the same time was not beneficial.
- It is difficult to identify carers, especially young carers and carers of people with mental health problems.

2.4 Paignton and Brixham GP Carers Project (ID number 36; evidence category B3)

Description of intervention

The Paignton and Brixham GP Carers Project began in April 1996 and ended in September 1997. The idea originated in discussions between social services and GPs (one in particular); the idea was turned into a reality due to the availability of monies from Special Transitionary Grant budget slippage. South Devon Carers' Consortium took on the management and delivery of the service. In Phase 1, two carers workers were based in three practices for half a week each (the project did not proceed in a fourth practice). In Phase 2, one worker continued in two practices, and the other had a 'roving' brief, working with a number of practices but not based in any of them. The intention in Phase 2 was to focus on more practices in an influencing and educating role, rather than emphasising direct work with carers. In this way, the effect of the project would still be felt even after it had ceased to operate.

Barriers addressed

Professional characteristics; service issues; information and knowledge issues. The project aimed to improve carers' access to health care by: identifying carers; developing new ways of assessing the needs of carers; promoting and developing a range of appropriate networks and services to meet the needs of carers; promoting awareness of carer needs within the primary health care team; signposting carers to other agencies and information sources.

Evaluation

An independent evaluation of the project was undertaken when Phase 2 was completed. Source material for the evaluation included: interviews with key professionals in South Devon Carers' Consortium, Social Services and the health authority; questionnaire responses from practice team members and carers; contract documentation; minutes of meetings; copies of relevant correspondence; interim and final project reports.

Outcomes

All three of the practices in Phase 1 had developed ongoing support systems for carers, as had one practice in Phase 2. New carer support groups were established. All carers' records were tagged, either with stickers for paper notes or on computer records. Overall, the evaluators judged that the project had made a positive contribution to the well-being and empowerment of carers.

Strengths of the structure, process and outcomes of the intervention

The involvement of the South & West Devon Health Authority in Phase 2 was believed to have given the project 'respectability' and opened doors to the roving worker in more practices.

The roving worker was able to reach more practices and identify more carers, suggesting that this approach was more cost-effective. However, the workers based in practices did more in-depth support of carers, which might have had more impact on the work of health professionals in the practices.

The objective of building (new) support systems within the practices was to ensure that the work for carers could continue after the end of the project. There were grounds for optimism for the sustainability of these services, particularly in view of the fact that the South Devon Carers' Consortium, an infrastructure body, was ideally suited to offer continuing support and information. Having said that, there were tensions and conflicts. For instance, at least three practices declined to access funding for services for carers which would last beyond the life of the project even though the opportunities were there. This was felt to be linked to a lack of wholehearted support by GPs in particular, and practices in general.

Weaknesses of the structure, process and outcomes of the intervention

It was felt that not enough time was spent exploring the different values and expectations of all the stakeholders prior to the start of the project. Initially, Social Services viewed the project as experimental. A revised contract, with a sharper focus on 'hard' outputs and more defined activities, moved away from this concept resulting in less flexibility for responding to developments as they arose and less opportunity for longer-term educational work in the practices. This had the potential to prejudice long-term beneficial effects.

There was concern about raising carers' expectations, as the project funding was short term and non-recurrent, but, in the view of South Devon Carers' Consortium, its aims were long term.

Practical issues concerning deficiencies in accommodation, office support and equipment created difficulties for the carers workers. There could also be problems in respect of integrating with members of the primary health care teams. Carers workers experienced a lack of referrals from GPs. Confidentiality concerns meant that workers were not always able to contact carers direct.

Monitoring arrangements fell down when the Social Services initiator of the project left her post shortly after the project started. Targets were not set and benchmarks not recorded, making it difficult from the statistics recorded to determine what impact the carers workers were having compared to what was happening in the practices before the project started.

The medical model and the hierarchical organisations that many GP practices implement may not easily fit with a project designed to explore new ways of meeting what amounts to non-medical needs.

In the Paignton and Brixham GP Carers Project, it was hard to obtain GP commitment and involvement. Consequently, the carers workers tended to focus on activities with carers rather than trying to affect the overall culture of the practice in question.

Key learning points

- The more self-sufficient a carers worker can be, the easier it is for a GP practice to get involved in a carer support project.
- The professional status of the carers worker can be influential in terms of acceptability within the practices in which they worked. There were indications that a medical background was particularly helpful.
- GP practices need to explicitly sign up to the aims, expectations and processes of carer support projects.
- There should be clear and explicit agreements between all the stakeholders in any project, to try to deal with potential future difficulties in advance.
- Time should be spent at the outset of a project on designing the process and presentation of agreed monitoring statistics; this would help clarify how realistic expectations are in terms of possible outputs and outcomes.
- All senior GPs should be thoroughly involved in and committed to the project in the planning process.
- When initiating an innovation that might require the collaboration of primary health care teams, the sustained input of the local health authority (or equivalent) may be necessary from the outset, to assist in securing and maintaining their continued commitment.

2.5 Cornwall Carer Support Workers Service (ID number 37; evidence category C1)

Description of intervention

The Cornwall Carers Support Workers Project was set up in July 1996. Five GP practices were provided with the services of a part-time carer support worker for a period of two years. The Cornwall and Isles of Scilly Health Authority funded the five workers, and was responsible for their training. At the county level, the Cornwall Rural Community Council (CRCC) managed the implementation of the service, which was overseen by a multi-agency project

steering committee. Locally, the service was overseen and monitored by a practice advisory committee for each of the five participating GP practices. At the end of the two-year pilot period, the carer support workers were withdrawn. They were replaced by identified 'practice carers' contacts' in four of the GP practices, who took on the work previously undertaken by the carer support workers.

Barriers addressed

Professional characteristics; service issues; carer or care recipient characteristics; information and knowledge issues. The original project aimed to improve carers' access to health care by, for example: helping GP practices and primary health care teams identify and support carers; improving accessibility to information, advice, counselling, support and assessment for all carers; encouraging carers to become actively involved so that the project evolved as they wanted; ensuring that GPs, primary health care teams and social services were more knowledgeable about carers' needs, and viewed them as partners in the caring process.

Evaluation

The services provided by the practice carers' contacts were evaluated in 2000 by an independent researcher. The aim of the study was to investigate the extent to which systems and procedures instigated by the four carer support workers had been maintained by the practice carers' contacts some 18 months after the departure of the original workers. Two questionnaires were designed to collect information from the four practice carers' contacts, and a random sample of five carers from each practice. We have not been able to obtain a copy of a report produced in 1998 on the original pilot project.

Outcomes

Many carers were able to identify the practice carers' contact at their surgery. They were provided with information and support, if not immediately then usually within one week. Overall, the results suggested mixed success in terms of the lasting impact of the carer support worker service first implemented within the practices. While the role of the carer support worker had been clearly identified, not all these functions were being maintained by the practice carers' contacts. The provision of information to carers, for example, was the only task undertaken at all four practices. All the systems required to maintain a register of carers, to identify and record patients who were carers, and to maintain a recall system for patients were in place in one practice only.

Strengths of the structure, process and outcomes of the intervention

The carers interviewed appreciated the services offered, and felt supported by their practice carers' contact. However, not all carers knew who their identified practice carers' contact was, yet they all knew who the original support worker was.

Weaknesses of the structure, process and outcomes of the intervention

There were differences in the roles held by the practice carers' contacts. One was a volunteer working for a carer support group and not employed by the practice; another was a community nurse employed by the Community Health Trust; a third was a practice receptionist employed by the practice in question, and the fourth was the district nurse employed by the practice. It is possible that reasons why systems were not being maintained were related to these distinctions. More of the identified tasks of the carer support worker were being performed in the two surgeries where the practice carers' contact was actually employed by the practice.

Two of the carers' contacts felt they did not have the skills required for dealing with carers (for example, counselling skills), because they were not professionals. The fact that one was a carer herself was inhibiting for some of the carers, who felt they could not share their feelings as they perceived a lack of professional expertise.

In the two practices where the carers' contacts were also nurses, carers did not always differentiate between the two roles.

The practice carers' contacts did not have time to follow up individual carers, whereas the original carer support worker had made a point of contacting all the carers.

Key learning points

- Consider employing an individual within each practice, or shared between several practices, dedicated specifically to the role of carer support worker.
- Agree the key elements of the role of the carer support worker and determine what should be provided on a routine basis by the identified practice carers' contact.
- Determine an appropriate monitoring procedure to identify which elements of the role are effective and which are ineffective.
- Regularly review the role of the carer support worker at a practice level, and provide appropriate support.

2.6 Brent Primary Care Project (ID number 38; evidence category B3)

Description of intervention

Brent Carers Centre has been working with GP practice staff since the early 1990s. Since 1999, the Brent Carers Project has been funded by Brent Health Action Zone. Two project workers were employed across Brent; they were physically based at the Primary Care Trust offices (previously the Primary Care Group). The workers were jointly managed by senior workers in the Primary Care Group/Trust (PCG/T) and the chief officer from Brent Carers Centre. Some 30 per cent of the workers' time was allocated to working directly with carers, and the remainder to development work with primary care services.

Barriers addressed

Professional characteristics; service issues; carer or care recipient characteristics; language or cultural issues; information and knowledge issues. The project aimed to improve carers' access to health care by: identifying carers; providing carers with information, advice, practical help and training; promoting awareness of carers' needs within the primary health care team; forging links and developing networks with primary care managers and with GP practice staff through PCG/T training, development and strategy meetings.

Evaluation

The project was evaluated in 2002 by two independent researchers, with funding by Brent Carers Centre. The aim of the evaluation was to explore what had worked well, what the challenges were, and future developments. Semi-structured interviews were undertaken with a range of key stakeholders: carers who had received support from the project workers; staff at randomly selected GP practices; the project workers; primary care managers. Carers also completed training evaluation forms.

Outcomes

Seven of the ten GP practices contacted had implemented some type of system for identifying or tagging carers' records, however, the remaining three had no mechanisms in place at all. Seven surgeries displayed material from Brent Carers Centre; an information pack was highly valued by both practice staff and carers. Carers received one-to-one advice and support (including completing attendance allowance or disability living allowance forms), and appreciated time to talk about non-medical issues. The project workers co-ordinated a series of training sessions for carers. They were perceived to have raised awareness about carers' experiences and needs among staff working at a strategic level within primary care, and also had impacted on projects beyond primary care. While the report emphasised the importance of actively attempting to reach carers from different minority ethnic groups, especially

those who did not speak or read English as their first language, the extent to which this was realised in practice was not made clear in the report.

Strengths of the structure, process and outcomes of the intervention

The evaluation identified a range of features that appeared to facilitate GP support for carers. The project workers were physically located within PCG/T, so were visible to both strategic and practice-level staff. This positioning allowed working relationships to develop and provided an ongoing reminder that carers were an important issue.

While it was thought to be unusual for the voluntary and statutory sector to work so closely together, there were advantages to joint management by primary care and Brent Carers Centre: shared 'ownership' and responsibility for progress and success; access to expertise within, and information about, both organisations; access to meetings, staff and their networks in both agencies; the workers being viewed as central PCG/T staff. Likewise, joint supervision generated advice and personal support from senior managers in both organisations.

The inclusion of formal monitoring standards for carers in the GP Practice Development Plans in the (former) Brent North PCG area provided an important incentive for practices to implement carer systems.

Weaknesses of the structure, process and outcomes of the intervention

All the GP practice staff had high workloads, and the full implementation of systems to identify/support carers was just one priority amongst many. Pressures on available time, staff and financial resources meant that not all practices felt they could implement carer systems, and/or did not place carers' issues as high on the agenda.

The two carers workers were covering a total of 74 GP practices, as well as undertaking individual casework for 30 per cent of their time. Similar projects might employ workers whose remit is to support a smaller number of surgeries but on a more intensive basis.

Workers found it could be difficult to manage the casework and development work roles. Whilst casework was valued, it was time consuming and sometimes viewed as a distraction from development work with GP practices.

Key learning points

- Asking a question about carer status on repeat prescription forms was a particularly useful mechanism to identify carers who were not registered at the same surgery as the person they supported.
- Staff with personal experience of caring and/or a real understanding of the carers' situations were more likely to implement carer-focused systems within their surgeries.

- Surgeries with at least one GP or practice manager 'on board' were more likely to allocate time and resources to identifying and supporting carers.
- Carers workers were most effective when they built up close working relationships with strategic and GP practice workers.
- GP practices implemented unique sets of systems for carers that suited their particular surgery's size, staff mix and working culture. There was no one ideal 'blueprint' to suit all practices.
- Having visible workers in post, with the specific role of promoting carers' needs, was very effective.
- GP practice staff willing to act as 'champions' and promote the benefits of implementing carer systems to other surgeries should be identified and utilised.
- Primary care trust monitoring and incentive schemes should be exploited to promote carer awareness and the implementation of systems. Carer monitoring standards should be established, and carer-related agreements built into new GP contracts.
- Advertising through community resources, such as places of worship, post offices, local shops and papers, could be useful for targeting carers from black and ethnic minority communities.

Section 3 Guidelines and toolkits

To complement this review of primary care evaluations, we would like to draw attention to eight recently published guidelines and 'toolkits' aimed at helping health (and other groups of) professionals examine and improve their support for carers. The guides are practical, focusing on issues that have come to the fore since the launch of the National Strategy for Carers (Department of Health, 1999). While we found no studies that had evaluated how useful they were, they do touch on issues relevant to carers' access to health care. The evidence base is stronger for some of the documents than for others, and in each case we have indicated the type of evidence according to the study design typology. Making reference to the guidelines and toolkits in a report such as this may:

- contribute towards overcoming some of the barriers that carers face
- reduce time spent by professionals in 'reinventing the wheel', and
- encourage wider usage with a view to some form of assessment of their value.

3.1 Guidelines for Primary Health Care Teams: South Asian Carers' Project *(evidence category B3)*

Based on their study of South Asian carers, Katbamna and colleagues (1998a, 1998b) have developed guidelines aimed at providing recommendations to assist members of primary health care teams in their work with carers from this community. Some of the topic areas covered in the guidelines include communication, information and recognition – particularly in relation to cultural and religious beliefs. These go some way to filling the gap noted earlier, namely the lack of primary care initiatives targeting ethnic minority carers.

3.2 Taking Action to Support Carers: A carers impact guide for commissioners and managers (evidence category C1)

This practical guide was published by the King's Fund, and is based on empirical research findings from the Carers Impact programme. The authors, Banks and Cheeseman (1999), include a checklist of questions for primary care teams to ask of themselves in order to judge whether or not they are meeting carers' key needs, including their wish to be recognised and have their personal needs for health and social care met.

3.3 How Good is your Service to Carers? A guide to checking quality standards for local carer support services
(evidence category C1)

The third guide (Blunden, 2002) was also published by the King's Fund, and draws on extensive pilot work in various parts of the country. It is designed to help service organisations assess how well they are meeting a set of five quality standards for local services to support carers which were developed as part of the National Strategy (Department of Health, 1999). Standard 4 covers any service that supports carers to care and maintain their own health and well-being. This includes promoting good health for carers, which may mean 'sessions to assist carers to look after their own physical and emotional health, relaxation and other therapies' (p. 36). Complementary therapies delivered in carers' own homes are discussed later in the report.

3.4 'Seven and a Half Minutes is not Enough': A good practice guide for carers, support workers and GP practices
(evidence category C2)

This good practice guide was published by the Princess Royal Trust for Carers (PRTC) in 1999 (Warner, 1999). The information included was based on interviews and visits to three PRTC centres working within primary care practices, one of which was Brent Carers Centre, discussed earlier in this report. The guide makes suggestions to help GPs, primary care practices and carer support projects develop effective support for carers, including how to identify carers. There is some anecdotal information about cost-effectiveness, but the author stresses that judging the effectiveness for GPs of providing support for carers requires detailed record keeping by the GP practice as a whole. Suggested measures include: appointment times and overruns; inappropriate enquiries; prescription needs; emergency and out-of-hours enquiries; stress, exhaustion, back injuries and other carer-related symptoms.

3.5 Identifying Carers in General Practice
(evidence category C2)

The Spinney Practice in St Ives, Cambridgeshire, was awarded 'Beacon' status in 1999 for its Carers Project Group. A document containing a model for identifying and supporting carers has since been published (Spinney Carers Project, 2001) based on the experiences of the carers project and hosting Beacon Workshops. The model can be developed to suit the level to which a GP surgery is prepared to get involved, and contains essential features (administration; raising awareness) for every model and optional additional features (identifying carers; raising awareness in the GP practice and among patients; support; liaison information) which different GP practices may use

according to the needs and interests of the patients/carers, the surgery's level of interest and time constraints.

3.6 How to Ensure your Service is Responsive to the Needs of Carers
(evidence category C2)

Another local initiative, the Newcastle Carers Project, has produced a 'guide and action planning tool' (Newcastle Carers Project, 2002). Local carers and health service staff were involved in developing the guide, which is intended for use in a range of health care settings including GP surgeries. The guide focuses on both process and outcomes, and suggests that health professionals first discuss with carers what outcomes they need and expect from community and hospital-based health care services. Follow-up work includes developing structures to ensure that the processes of service delivery achieve carers' desired outcomes.

3.7 'A guide for assessing caregiver needs: determining a health history database for family carers'
(evidence category C2)

A guide for doctors to use to assess the health of carers and provide a database on which to establish an action plan has been developed in the US (Melillo and Futrell, 1995). The guide was critiqued by ten expert practitioners in the fields of gerontology, gerontological nursing, nursing research and primary care. The guide asks for information about the carer, their health status, employment, resources available, relationship with the care recipient, and their rating of the latter's health and behaviour. The intention is that the doctor has an opportunity to prevent serious health problems for the carer by suggesting health promotion strategies, resources or educational programmes. It can be inserted into the carer's medical records and periodically reviewed during visits to the doctor.

3.8 Healthcare for Carers
(evidence category C2)

Finally, a *Healthcare for Carers* pack aimed at carers of people with Parkinson's disease has been developed as the result of a collaborative partnership between Pharmacia (a pharmaceutical company), the South West London Community NHS Trust and a number of patient groups (Pharmacia, 2002). The pack has three components, and can be downloaded from the Internet: www.healthcareforcarers.co.uk. *Help Yourself to Health* is a booklet for carers to keep for themselves and is designed to assist them to think about their own health. The *Health Check for Carers* is designed for the assessment of carers' health needs by a health care professional (family doctor, or Parkinson's disease nurse specialist), to be kept with their medical notes, and

complements the information gathered by carers in their *Help Yourself to Health* booklet. The *Educational Pack* is designed to provide information and materials to meet the various health needs of carers. The intention is that carers use the booklet to help them think about their own health needs and on their next visit to the doctor or practice nurse identify themselves as carers and request an assessment of their own health needs. It is hoped that the pack may be opened up to a wider audience of carers, including those caring for people with long-term conditions such as arthritis and cancer. See Thomas and Sweetnam (2002) for a discussion of how the pack is being trialled by carers living within Cornwall.

Section 4 Home-based health care projects

4.1 Telephone carer groups (ID number 39; evidence category B2)

Description of intervention

Over a two-year period, the Glenrose Rehabilitation Hospital (Edmonton, Canada) used a quasi-experimental design to compare the impact of telephone carer groups with traditional face-to-face on-site carer groups. Carers participating in the study supported adults with a brain injury. Both types of groups met weekly for nine to ten weeks; groups were led by a psychologist, a neuropsychologist or a social worker from within the Brain Injury Programme. A wide range of topic areas were covered, including dealing with stress, ways to cope, and community resources. The telephone group used teleconferencing technology.

Barriers addressed

Service issues; information and knowledge issues. The telephone carer groups aimed to overcome access problems faced by rural carers because of the distance they lived from treatment centres in relation to support from health care professionals. By providing counselling, skills development and education, carers benefited by learning about, for example, stress management techniques, coping strategies and available services.

Evaluation

Professionals at the hospital evaluated the two types of groups using standard outcome measures examining family functioning, carer burden and carer stress. Pre- and post-test measures were taken, which were also repeated six months after the last day of the group. In addition, a satisfaction questionnaire was administered at the last group session.

Outcomes

Carers were all keen to seek help in order to deal with the stress associated with coping with someone with a brain injury. The results showed there were similar amounts of improvements for the outcomes from both types of groups. However, rural carers taking part in the telephone groups reported experiencing lower carer burden, less reported distress and fewer difficulties in family functioning than did carers in the on-site groups. Furthermore, telephone group participants reported slightly higher levels of satisfaction. The researchers concluded that the use of telephone technology for groups was a way of providing a specialty health service accessible to carers who are geographically isolated from urban treatment centres, and in this way could bridge the inequities in access to services for those living in rural areas.

Strengths of the structure, process and outcomes of the intervention

The researchers were anxious that the lack of personal contact for telephone group carers might have had a detrimental effect. In fact, these participants reported slightly higher satisfaction levels, leading the researchers to speculate whether the anonymity provided by the telephone and the convenience of receiving the service at home were beneficial.

The costs of delivering services by long-distance teleconferencing averaged $375 per person for a nine- to ten-session group series. Given the expenses associated with alternative strategies, for instance sending professionals to rural communities, the researchers concluded that telephone groups provided a cost-effective method of providing support to carers who lived outside an urban centre. They noted that since the study ended, the hospital has been able to reduce long distance costs considerably.

Weaknesses of the structure, process and outcomes of the intervention

The authors reflect on limitations to the study (for instance, relatively small sample size), but do not report on any weaknesses in relation to arrangements for either the telephone groups or the on-site groups.

Key learning points

- Telephone groups offer a method of providing support and education to rural/isolated carers that appears to be as effective as traditional in-person on-site groups.
- Telephone groups are a cost-effective way to support carers who live outside urban centres.

4.2 ComputerLink
(ID number 40; evidence category B1)

NB: Exceptionally, this account also draws on three other articles about ComputerLink, which included more detailed information about methodology, strengths and weaknesses of the system (Brennan *et al.*, 1991; Brennan *et al.*, 1992; Bass *et al.*, 1998).

Description of intervention

ComputerLink was a computer support network for carers of people with Alzheimer's disease. The most widely used feature was the communications component, which included a private e-mail system, a public electronic bulletin board and a question-and-answer segment facilitated by the nurse moderator. In addition, there was also a four-module electronic encyclopedia on Alzheimer's disease and its treatment, management of symptoms, services for Alzheimer's patients and carers, and self-care for carers. This component also included a decision-support module that helped carers address unsolved

problems and dilemmas. ComputerLink was accessible 24 hours a day, seven days a week, and was housed on the Cleveland public access computer network Free-Net. Terminals were installed in carers' homes by a project nurse, who also provided training lasting about 90 minutes.

Barriers addressed

Service issues; carer or care recipient characteristics; information and knowledge issues. ComputerLink helped overcome logistical problems in obtaining transportation and/or finding substitute care in order to leave the home. Carers could obtain psychosocial support, information and advice from health care professionals and other carers. By discussing their situation anonymously, some of the barriers carers might perceive in face-to-face interactions were removed.

Evaluation

ComputerLink was evaluated in a 12-month randomised controlled trial. Out of the full sample of 96 carers, some 47 were allocated to an experimental group and received a terminal modem system (cost covered by grant funds); 49 carers in the control group did not have access. Pre- and post-intervention data collection included a mix of standard outcome measures and also items developed specifically for the project. ComputerLink usage was measured, and a content analysis of carers' messages to the public bulletin board was undertaken

Outcomes

Overall, ComputerLink appeared to be an effective tool for reducing strain for some carers. Reductions in strain were greater for carers with more informal support and for spouse carers. ComputerLink provided three types of psychosocial support: instrumental (the provision of information about methods of assistance, and community, home care and self-care resources available to carers); emotional (sympathy, understanding and a sense of community); and spiritual (the offering of scripture, prayer or inspiration).

Strengths of the structure, process and outcomes of the intervention

ComputerLink was accessible 24 hours a day and hence could provide support outside professional office hours. This ready availability meant that carers could use the system at times that were convenient for them, without having to leave home and/or fit in with the schedules of professionals or other carers. Because the computer messages posted to the computer remained permanent, the content could be retained and accessed for long periods of time.

ComputerLink facilitated direct contact with a project nurse. The resources available to the nurse meant that she had easy access to knowledgeable clinical nurse specialists and national associations specialising in particular disorders.

The (written) social interaction between network members permitted the sharing of options and opinions. Members could place messages anonymously; anonymity was advantageous as embarrassment and perceived stigma could inhibit carers from seeking help. Because carers were not interacting face to face, this had the potential to reduce embarrassment and anxiety, allowing people to be less inhibited about expressing their feelings.

Weaknesses of the structure, process and outcomes of the intervention

Initial technical problems with installing the computer in their homes led to three carers in the ComputerLink experimental group dropping out shortly after assignment and taking no further part in the project. Feeling uncomfortable with the computer resulted in another carer opting out.

A common frustration or annoyance with the system was coping with busy signals when all phone lines to the system were in use, and recalling the electronic mail addresses of other users.

Standard telephone access was not available to the household whenever the carer used ComputerLink. ComputerLink also required changes to the location of furniture.

Key learning points

- The short training period of about 90 minutes shows that inexperienced users can be taught to use a computer network successfully.
- The average age of carers in the experimental group (68 years) supports the assertion that there can be acceptance and use of a computer network by those who are not typical computer users.
- Prior experience with a computer and level of education do not appear to be critical to the successful use of this sort of technology.
- The effects of systems such as ComputerLink are unlikely to be uniform for all carers, but will depend on initial vulnerability and circumstances; it should not be assumed that the more vulnerable carers will experience greater benefits.

4.3 Telematics intervention: the ACTION project (ID number 41; evidence category B3)

Description of intervention

ACTION was a three-year project involving a number of European countries (England, Northern Ireland, Portugal, Republic of Ireland, and Sweden), running between 1997 and 2000, and funded by the Telematics Applications Programme, Disabled and Elderly section of the European Union Fourth Framework DGXIII. The service has also been implemented in Australia, New Zealand and North America.

The ACTION system, located in formal care settings and the homes of some carers, comprised video-telephones and multimedia to provide direct support and information to carers and care recipients. The video-telephones permitted direct contact with professionals, the research site and other carers. The multimedia programmes were accessible through video or computer and covered a wide range of topics, including lifting and handling, information about respite services, and developing coping skills for carers. Internet and e-mail facilities were made available to a number of carers.

Barriers addressed

Service issues; information and knowledge issues. ACTION was aimed at reducing access (and isolation) problems for carers living in remote areas or who could not leave their homes. It sought to provide information, education, advice and support to carers and care recipients in order to improve their autonomy and quality of life.

Evaluation

The service went through two demonstration and evaluation phases, addressing the benefits, acceptability and cost-effectiveness of the ACTION system and services. Multiple data collection methods were used, including questionnaires, log diaries, field notes and interviews with carers, care recipients (if possible) and professionals. A full economic evaluation to examine cost-effectiveness has not yet been possible.

Outcomes

Carers reported that ACTION helped to increase their competence in their caring role because it helped to develop their knowledge and skills. ACTION helped to support carers in other ways: by reducing their sense of isolation because it let carers know that they were not on their own; a sense of presence was created because carers could see one another; and by providing easier access to care professionals through the use of the video-telephone facility. The video-telephone for carers created effective informal social support networks.

Strengths of the structure, process and outcomes of the intervention

After initial anxiety about using the system, carers found it valuable, simple to use and of direct benefit to them in the caring situation. Helpfulness of the system was rated highly; attractiveness and efficiency were also rated above average. ACTION empowered carers and improved their sense of well-being; they did not need to go through a professional for information and the system permitted a preventive approach by helping carers and care recipients to plan for the future and make appropriate choices, by providing information.

ACTION cut down on travelling time for professionals, because follow-up consultations could be done via the video-telephone. This freed up time to deal with people with more intensive nursing needs.

Weaknesses of the structure, process and outcomes of the intervention

Some carers reported difficulty with navigation, finding there were too many selection programmes or 'getting lost' in the system (which could be overcome by introducing an index and search facility). Appropriate training and ongoing support were needed to help carers gain more confidence in using the system.

Professionals reported that learning to use the system themselves, in addition to supporting patients and carers to use the system, was time-consuming.

Care providers, administrators and managers thought that even though the cost of ACTION would become cheaper, expenditure on equipment was probably too prohibitive for many older people and their carers. An alternative was for ACTION to be adopted by health and social care providers.

Key learning points

- It is important to introduce this type of service to carers (and care recipients) as early as possible so that carers can get maximum benefits right from the start.
- An optimal environment for using ACTION needs to be created, in other words the location of the system is important. If the system is placed in a less than desirable setting in the household, then it is less likely that it will be used. Potential community settings include health and social care agencies, libraries, voluntary organisations, offices, pharmacies.
- Nearly half of the field study carers were aged 65 and over. The evaluation suggested that with education and support older people were able to use information and communication technology (ICT) effectively. It also noted that while only a small proportion of older people in Europe currently have experience of, and access to ICT, the rate of acceptance of systems such as ACTION will increase reflecting the ageing population's increased computer literacy.
- The evaluation does not point to a blanket use of technology such as the ACTION system, but rather to the considered use of such technology with individual carers and their families to ensure the positive aspects are fully realised and the negative aspects kept to a minimum.

4.4 Relaxation distance learning audio tape (ID number 42; evidence category C1)

Description of intervention

This pilot scheme followed on from a series of short courses for carers held in 1996 and run by Care for the Carers (Lewes, East Sussex). Care for the Carers

organised the production and distribution of a relaxation distance learning audio tape. This was made by a qualified and practising psychotherapist with considerable experience of working with carers. Carers took part in a one-month trial of the tape in June 1997. The aim of the scheme was to determine if the tape could be beneficial to the health of carers by reducing stress levels. Funding of £400 for the project was provided by a Health of the Nation grant.

Barriers addressed

Service issues. Although the project's primary aim was to improve carers' stress levels, it also had the potential to improve carers' access to health care by supplying carers with a relaxation tape to use in their own homes.

Evaluation

The evaluation was undertaken by Care for the Carers, and involved 21 carers completing questionnaire diaries about themselves and their health at three points in time: before completing the trial; on completion of the one-month trial of the tape; in June 1998, some 12 months after the trial had finished in order to find out what lasting benefits the tape had provided. The sample comprised 16 women and five men. Four carers were in their 60s, and seven in their 70s. The majority suffered health problems of their own, including back problems, arthritis and stress.

Outcomes

13 carers reported that their major stress factors had reduced immediately after the one month trial of the tape. The same number, 13, reported positive changes in their outlook. Carers made positive comments about an increased ability to recognise stress symptoms and to consciously take action to help relaxation. Seven carers still used the tape on a regular or intermittent basis some 12 months later, because they continued to find it beneficial.

Strengths of the structure, process and outcomes of the intervention

Many carers could not attend an earlier pilot scheme comprising a series of short courses because the person they supported needed constant care, or they did not feel confident leaving the person alone. The relaxation component of the series was seen as helpful in improving carers' quality of life. Putting sessions on to a tape for carers to use as and when they had the time or needed to practise overcame these logistical problems.

Weaknesses of the structure, process and outcomes of the intervention

A range of criticisms were made about the tape, including that it was boring and repetitive, the voice was irritating and it was too long. Most carers using the tape, however, said they would consider purchasing an improved version of the tape for up to £5.

Key learning points

- There are some carers who, because of their home circumstances, would prefer to practise relaxation techniques at home.
- Incorporating music and a variety of voices should make for a more interesting tape, while a professionally produced tape should improve its quality.

4.5 Telephone-linked care (ID number 43; evidence category B1)

Description of intervention

Telephone-linked care (TLC) was a telephone-based intervention sponsored by the National Institutes of Health, National Institute on Aging and the National Institute of Nursing Research (USA) as part of the Resources for Enhancing Caregiver Health project. The intervention comprised a 'round-the-clock' computer-mediated interaction voice response (IVR) system integrated with voicemail. Its overall aim was to help carers of Alzheimer's disease patients manage disruptive behaviours exhibited by the care recipient via different options. A monitoring and counselling option that provided a weekly IVR conversation asked carers about the number and type of disruptive behaviours they were managing and the associated stresses. The information carers supplied then generated advice and suggestions for management strategies. If stress and disruptive behaviours increased over the month, a computer-generated alert was triggered and faxed to the designated health or social service provider. An in-home support group option offered personal and carer group voicemail, allowing carers to ask questions anonymously and receive replies which were then stored in the telephone mailbox for them to listen to at their convenience. The 'carer respite' conversation facility provided an 18-minute automated tailored telephone conversation for the care recipient. There was opportunity for the care recipient to respond but if no response was detected the conversation continued. Carers could initiate the call and pass the phone to the care recipient as a diversionary activity, thus acting as a mini-respite break.

Barriers addressed

Service issues; information and knowledge issues. TLC addressed service issue barriers by facilitating access to health professionals without the carer having to leave their home. The 'Ask the Expert' facility gave carers voicemail access to a multidisciplinary expert panel for advice, referrals, or second opinions.

Evaluation

Researchers from the Hebrew Rehabilitation Center for Aged and New England Research Institutes (USA) conducted an 18-month randomised controlled study to measure the utilisation of the system, and identify the factors influencing use by looking at machine usage and users' subjective impressions. Interviews

and content analysis of users' impressions of the system were undertaken to discover what system features encouraged or discouraged usage. Data were obtained from 42 TLC participants and 49 control group members. The majority of the TLC group were women (80 per cent); the mean carer age was 60 years.

Outcomes

The evaluation found that, over the period of the intervention, the total system usage per user was 55 minutes, with an average of 11 calls per participant. Half of the participants used the system for at least 22 minutes, and a quarter for at least 70 minutes. Usage fell over the first four months and levelled out thereafter. The most frequently used option was the weekly carer conversation. This option made carers feel more knowledgeable and was helpful with managing behavioural problems. The second most popular option was the respite call, which was used to keep the care recipient occupied, allowing the carer to focus on other activities. The 'Ask the Expert' facility and the bulletin board option were the least used, owing to people receiving care at medical centres and for technical reasons. Face-to-face contact was preferred. The authors speculate that rural users might be more likely to use a telecommunications-based service.

Strengths of the structure, process and outcomes of the intervention

Participants reported that using the TLC system was not difficult. The weekly carer conversation was reported to be informative, helpful and easy to use.

Weaknesses of the structure, process and outcomes of the intervention

There was resistance to the project from health providers, who were concerned at substituting IVR technology for human interaction. There was also concern in some areas that the TLC system might threaten jobs.

The system intermittently failed to function as designed during the study. For example, there were occasions when a specific option did not work properly due to software problems. Study participants were sometimes disconnected at the beginning of telephone calls because of difficulties in authenticating passwords. Because a number of suppliers were involved in TLC, accountability was hard to determine/enforce when problems arose.

Participants who experienced technical problems during their first few calls were less likely to adopt TLC; technical problems were the most frequently reported reason for non-use of the system generally and for individual options.

Some individuals reluctant to use the 'carer respite' conversation facility said that past inappropriate behaviour by the care recipient led them to restrict the latter's use of the phone, and carers remained unwilling to encourage them to start using the phone again.

Key learning points

- Those people who made most use of the system were older, more highly educated, and more likely to have been rated as highly proficient by the trainer after the technology training session.
- People with a low tolerance to technical problems may be less likely to use this type of intervention. Being too busy because of caring demands is also likely to reduce usage.
- Training people until they are highly proficient may increase usage.
- A respite telephone call option offers the opportunity to provide carers with a small break.
- It is important to clarify at the outset responsibility for technical problems so that they can be dealt with efficiently.

4.6 Massage for primary carers
(ID number 44; evidence category C1)

Description of intervention

This small-scale project comprised a massage programme aimed at reducing the stress and fatigue that compromise the carer's ability to care effectively for a dying relative at home. The programme was managed by the Oregon Hospice Association, in conjunction with East-West College of the Healing Arts. Funding was provided by the American Massage Therapy Association. Carers received a series of full-body massages on a weekly or bi-weekly basis. The massage therapists travelled with their tables to the carers' homes. Swedish massage was the basic style of bodywork, but other techniques including Shiatsu, Reiki, and Polarity Therapy were integrated into sessions.

Barriers addressed

Service issues. The project had the potential to improve carers' access to health care as massages, aimed at reducing carers' levels of stress, took place in the carers' own home.

Evaluation

Some 13 carers were referred to the project, of whom 11 were women. The majority were over 60 years of age, the oldest being 82. Pre- and post-intervention data were collected on emotional stress, physical stress, physical pain and sleep difficulty.

Outcomes

Nearly all of those who participated in the massage programme reported reduced physical and emotional stress, reduced physical pain, and fewer sleep difficulties. The data indicated that carers having just three massages showed a similar decrease in stress by the end of their series, as did those having more than three.

Strengths of the structure, process and outcomes of the intervention

Being able to receive massage in the home was important given that many carers are reluctant to be absent, even for a short time, in case something should happen to the person they support.

Weaknesses of the structure, process and outcomes of the intervention

Carers who worked full-time faced difficulties in finding time in their schedule for appointments, and frequently cancelled or did not attend for sessions.

Key learning points

- Referrals are best made by staff who have direct contact with the family and know the family well (for example, social worker or nurse).
- Massage treatments were well received regardless of carers' age or previous massage experience; individuals making referrals should not let preconceived notions about who would or would not benefit from, or accept, receipt of massage deter them from offering people massage.
- The experience was most beneficial and successful with full-time carers.
- Continuing massage sessions even after the care recipient has died can help the carer feel supported and facilitate readjustment to their new situation.
- Use the services of certified or licensed massage therapists.

4.7 Mobile Therapy Unit
(ID number 45; evidence category B2)

Description of intervention

Allied Dunbar provided £50,000 over three years to fund a Mobile Therapy Unit established by the Dementia Care Trust, Bristol. The unit offered one of three complementary therapies (aromatherapy–massage, reflexology and Reiki) to client–carer pairs over four weeks in their own homes in order to relieve symptoms of stress and to increase feelings of well-being among carers and people with dementia. The project started in September 1999; funding has since run out and no other agency has stepped forward to offer more. The service is now no longer offered.

Barriers addressed

Service issues. The unit aimed to improve carers' access to health care by administering complementary therapies in peoples' own homes.

Evaluation

An independent evaluation of the unit's first year was carried out by a researcher connected to the University of Bristol. Data were collected for the second and third years, but resources were not available to analyse and write up the findings. Between October 1999 and September 2000, a total of 73 client–carer pairs registered with the unit. Some 55 pairs completed all four treatments. The majority of carers were women; nearly three-quarters were between the ages of 61 and 86 and had significant health difficulties of their own, particularly back problems and arthritis. Generally, ill health was the reason why some people either did not initiate treatment, or only completed between one and three sessions. Pre- and post-treatment questionnaires concerning clients' and carers' circumstances, health and well-being were completed. Four weeks after their last treatment, the 55 carers were interviewed over the telephone by the independent evaluator.

Outcomes

Carers found the treatments relaxing; nearly two-thirds claimed that the positive changes in their health and well-being were still evident three to five weeks after the last session. Nearly half of carers reported that clients enjoyed the treatments, and found them relaxing. Over one-third of clients were said to have sustained lasting benefit.

Strengths of the structure, process and outcomes of the intervention

For the first year, carers and care recipients were not charged for therapy sessions; however, in the second year they were going to be asked to contribute £5 per session if they could afford it. Each session cost about £28 to administer, which included management and supervision time, and the therapist's fee of £20.

The mobile unit occasionally made use of the Dementia Care Trust's relief caring service in the community by paying a relief carer to be with the person with dementia while their carer enjoyed a massage. The carer could then relax, knowing that the care recipient was in safe hands.

Weaknesses of the structure, process and outcomes of the intervention

Some carers were disappointed that the treatments had not helped either themselves or the care recipient as much as they had hoped.

The evaluation involved considerable form filling, as well as a telephone interview. This was a burden for many carers, and some were disturbed by a long list of questions about the care recipient's problems.

Key learning points

- Treatments were acceptable to, and effective with, carers over the age of 60.
- Clients and carers who completed all four treatments reported taking more medications than those who stopped. Furthermore, analyses of visits to the GP in the two months prior to the first treatment confirmed that client–carer pairs who completed the treatments on average visited their GPs more often than those who stopped their treatments. The report's author speculated whether willingness to seek medical help was associated with persistence with complementary therapy treatments.
- Reflecting funding constraints, it might be that after an initial number of weekly sessions, treatments could instead be offered fortnightly.
- Evaluation questionnaires should be streamlined both for the carers' sake, and to save administration and evaluation time.

Section 5 Geographical information systems software

5.1 GIS software
(ID number 46; evidence category B3)

Description of intervention

GIS software was applied to informal care planning, specifically respite care and short-term breaks, in the area of the two health authorities of East Sussex, and Brighton and Hove.

Barriers addressed

Service issues. By amalgamating different types of data, GIS can look at the distribution of different aspects of service provision, demand, accessibility and utilisation and in this way has the potential to manage short-term care service planning.

Evaluation

Research was undertaken in late 1995 and early 1996 by the University of Brighton to assess the awareness and application issues associated with the potential use of GIS to manage short-term care service planning for carers. The assessment involved interviewing key local managers and planners across a number of agencies. Two workshops were also held, the second of which worked through a SWOT analysis of GIS potential in health and social care planning.

Outcomes

Maps were produced showing, for example, the amounts of respite care received by carers in different parts of the county. Another one used the results of a qualitative survey of carers to map unmet need in the area. Many of the respondents were generally positive about the potential of GIS as a complementary planning tool, although implementation still needs a considerable amount of thought and development.

Strengths of the structure, process and outcomes of the intervention

It was felt that GIS was potentially valuable in the areas of service planning, planning for carers (and users) and the spatial modelling of service delivery. By looking at the distribution of the levels of need as expressed by levels of disability and mapping this against levels of provision, it was possible to further identify shortfalls and the lack of equity across the county, particularly in rural

areas. The consistency of patterns of provision, demand and need across the county could be examined.

Weaknesses of the structure, process and outcomes of the intervention

The technical processes involved in the collection of raw data and the derivation of the datasets stored in the GIS software are complex and time-consuming. Obtaining direct personal data, which is essential in any meaningful modelling of need and demand, may remain problematic as ethical issues associated with the use of individual and confidential data remain an obstacle in the further development of the use of GIS in this area. It is not clear as yet whether a GIS can actually deliver and successfully incorporate qualitative data related to need into a fundamentally quantitative structure. This is an issue to be re-examined in the light of the development of GIS systems and also in the light of the changing demands of health care planning.

Key learning points

- GIS needs to be tested more thoroughly to determine the level at which it can be applied, and to demonstrate the potential value of GIS to practitioners and planners in the field and more widely to carers and care recipients.
- The maps produced show how data can be analysed and used from a management and planning perspective, but it was not obvious that they really took into account carers' needs and issues.

Section 6 Conclusion

As noted at the start, this analysis has attempted to provide information about what works, for whom, in what circumstances. This was to help identify the potential ability of different types of interventions to address variations in access to health care for different groups of carers. As can be seen in Table 6.1, primary care interventions appear to work better for some groups than for others. Home-based health care projects have the potential to be useful to carers of all ages, and may be especially valuable for those living in isolated areas and/or those who find it hard to leave the house.

Table 6.1 Interventions' ability to address variations in carers' access to health care

Intervention	Types of carers who may benefit	Types of carers who may not benefit
Primary care initiatives	• carers with a visible presence in the GP surgery • older carers • 'hard-to-reach' carers • carers in need of advocacy	• young carers • carers of people with mental health problems • carers not registered at the same surgery as the person they support • carers who do not live with/geographically close to the care recipient
Home-based health care projects	• isolated carers • rural carers • carers with transport difficulties • housebound carers • carers with busy schedules • older carers • carers of any age and/or without any previous computer or massage experience • carers wanting anonymity	• 'technophobe' carers • carers who juggle full-time work with caring

For a detailed synthesis of how the different types of interventions addressed the five barriers to health care for carers, and more information about the strength of the evidence base, see Chapter 4 of the main report (Arksey *et al.*, 2003).

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Appendix 1 Typology of study designs

Evidence from empirical research and other professional literature	
Evidence type code	***Examples of study type***
A1	Systematic reviews which include at least one randomised controlled trial (RCT) (e.g. Systematic Reviews from Cochrane or Centre for Reviews and Dissemination)
A2	Other systematic and high-quality reviews which synthesise references
B1	Individual RCTs
B2	Individual non-randomised, experimental/intervention studies
B3	Individual non-experimental studies, controlled statistically if appropriate; includes studies using case control, longitudinal, cohort, matched pairs, or cross-sectional random sample methodologies, and sound qualitative studies; analytical studies including secondary analysis
C1	Descriptive and other research or evaluation not in B
Evidence from expert opinion (in the absence of empirical research evidence)	
Evidence type code	***Examples of study type***
C2	Case studies and examples of good practice
D	Summary review articles and discussions of relevant literature and conference proceedings not otherwise classified
E	Professional opinion based on practice, or reports of committees
U	User opinion from carers or carers organisations

Source: adapted from National Service Framework for Older People (Department of Health, 2001)

Appendix 2 Summary of intervention evaluations (n=14)

Primary care initiatives (n=6)

ID number	Author(s)	Intervention and aim	Carer Group	Barriers addressed	Research/ evaluation design	Study typology code	Setting
33	Naish and Benaim (1995)	Hackney and Newham GP–Carers Project To improve the amount and quality of support carers received through general practice	Generic	Professional characteristics; service issues; carer or care recipient characteristics; information and knowledge issues	Mixed methods: interviews and questionnaires	B3	UK
34	Lloyd (1996)	Newhaven Carers Project To promote and protect the health of carers	Generic	Professional characteristics; service issues; carer or care recipient characteristics; information and knowledge issues	Qualitative methods: interviews and attendance at meetings	C1	UK
35	Tarry (1998)	Carers Primary Care Project at Fairfield Surgery, Burwash To identify and assist carers	Rural	Professional characteristics; Service issues; carer- or care-recipient based; information and knowledge issues	Qualitative methods: interviews	C1	UK

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ID number	Author(s)	Intervention and aim	Carer Group	Barriers addressed	Research/ evaluation design	Study typology code	Setting
36	Stevens (1999)	Paignton and Brixham GP Carers Project To identify carers; to develop new ways of assessing carers; to develop networks and services to assist carers; to promote carer awareness within the primary health care team	Generic	Professional characteristics; service issues; information and knowledge issues	Mixed methods: interviews, questionnaires, contract documents, correspondence, minutes of meetings, interim and final reports	B3	UK
37	Morris (2000)	Cornwall Carer Support Workers Service To improve support for carers offered by primary health care practitioners	Generic	Professional characteristics; service issues; carer or care recipient characteristics; information and knowledge issues	Quantitative methods: post-intervention questionnaire survey	C1	UK
38	Morris (2002)	Brent Primary Care Project To provide carers with one-to-one advice, support and training; develop awareness of carers' issues in GP practices; support staff to implement carer-friendly systems; to develop networks with primary care managers and GP practice staff	Generic	Professional characteristics; service issues; carer or care recipient characteristics; information and knowledge issues	Mixed methods: interviews and training evaluation forms	B3	UK

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Home-based health care projects (n=7)

ID number	Author(s)	Intervention and aims	Carer Group	Barriers addressed	Research/ evaluation design	Study typology code	Setting
39	Brown *et al.* (1999)	Telephone Carer Groups To compare the impact of telephone carer groups with traditional face-to-face on-site carer groups	Rural	Service issues; Information and knowledge issues	Quantative methods: quasi-experimental	B2	Canada
40*	Gallienne *et al.* (1993)	ComputerLink (functions include communications networks, an electronic encyclopaedia, and a decision support module for carers) To provide support to carers of people with Alzheimer's disease, via ComputerLink	Alzheimer's disease	Service issues; carer or care recipient characteristics; information and knowledge issues	Quantitative methods: randomised controlled trial	B1	USA
41	Magnusson *et al.* (2002)	Telematic Inverventions (video-telephones and multimedia) To provide direct support and information to carers and care recipients via computer technology	Elderly	Service issues; knowledge and information	Mixed methods: semi-structured interviews, questionnaire, log diaries, field notes	B3	Europe
42	Lazarus (1998)	Relaxation distance learning audio tape To reduce carers' stress levels	Generic	Service issues	Quantitative methods: before-and-after study (uncontrolled)	C1	UK

* This entry draws on three other articles about ComputerLink, which included more detailed information about methodology, strengths and weaknesses of the system: Brennan *et al.* (1991); Brennan *et al.* (1992); and Bass *et al.* (1998).

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ID number	Author(s)	Intervention and aims	Carer Group	Barriers addressed	Research/ evaluation design	Study typology code	Setting
43	Mahoney (2001)	Telephone linked care To help carers of people with Alzheimer's disease manage disruptive behaviours by providing expert advice and support groups via the telephone	Alzheimer's disease	Service issues; knowledge and information	Quantitative methods: randomised controlled trial	B1	USA
44	MacDonald (1998)	Massage for primary carers To reduce carers' stress and fatigue	Generic	Service issues	Quantitative methods: before-and-after study (uncontrolled)	C1	USA
45	John (2000)	Mobile therapy unit To relieve symptoms of stress and to increase feelings of well-being among carers and people with dementia	Dementia	Service issues	Quantitative methods: quasi-experimental	B2	UK

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Geographical information systems (n= 1)

ID number	Author(s)	Intervention	Carer Group	Barriers addressed	Research/ evaluation design	Study typology code	Setting
46	Foley (2002)	Geographical information systems (GIS) To assess the potential applicability of GIS software through a study of carers and the provision of short term breaks	Generic	Service issues	Mixed methods: interviews and workshops	B3	UK

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