Support services for carers: methodological issues in evaluating the literature

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RESEARCH woRks

This *Research Works* offers guidance for individuals involved in evaluating the evidence base for support services for carers, drawing on lessons learnt from three reviews. Evaluating evidence to underpin policy making in health and social care presents both managerial and methodological challenges for researchers. Key learning points include:

Effective management of the review process is extremely important. The review protocol should set out the different stages of the review, making the aims, objectives and methods of the research explicit.

Poor indexing of key terms and the lack of structured abstracts for social care journals may necessitate the retrieval of many irrelevant references, with obvious resource implications.

Defining what 'effectiveness' means in the assessment of support services for carers is a key methodological challenge. Available measures of effectiveness appear to be unsatisfactory and there is an urgent need to develop sensitive, relevant and validated measures in this field.

Economic evaluation depends heavily on good quality effectiveness data. There is little recently published, good quality cost-effectiveness evidence in this area, much of this is difficult to interpret for the UK health and social care settings.

Quality appraisal using a generic set of questions and a typology of study designs enables policy makers to identify evidence that is 'good enough' to inform decisions.

The gaps in the evidence base highlight the need for further research in the form of well-controlled studies that appropriately combine quantitative and qualitative methods to assess effectiveness and cost-effectiveness.

Background

The UK government's commitment to implement evidence-based policy is demonstrated by the establishment of the National Institute of Clinical Excellence (NICE), the Social Care Institute for Excellence (SCIE) and the introduction of National Service Frameworks. If local service managers have access to the available evidence about what works, for whom, and at what cost this can help them to target resources and to achieve value for money. Reviews of published and unpublished studies are an important source of evidence.

Lessons from carrying out three reviews of evidence on support services for carers *(see Box 1)* are described below. In all three reviews, we assessed evidence of the effectiveness of services; reviews 1 and 3 also assessed cost-effectiveness.

Box 1

Review 1: services for informal carers of people with mental health problems

Review 2: access to health care for carers, and interventions to improve accessibility

Review 3: respite services and short-term breaks for carers of people with dementia

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Management Issues

Review protocol The protocol specified the plan that the review would follow to identify, appraise and collate evidence. The different stages of the review were set out, making the aims, objectives and methods of the research explicit for both the commissioners and researchers. Typically, reviews in this field require the input of a multi-disciplinary research team and the protocol clarified how the various elements of the research fitted together.

Searching The research teams took an inclusive approach to sourcing the research evidence. We searched relevant electronic databases and websites, checked bibliographies, and contacted key researchers, voluntary organisations and other stakeholders. The Information Scientist developed a search strategy wide enough to capture broad issues relating to carers and did not limit the strategy by study design. This reduced the risk of missing relevant studies, but resulted in large numbers of references to screen. Poor indexing of key terms (such as 'carer' or 'caring') and the lack of structured abstracts for social care journals meant it was often difficult to discern whether the study would be helpful to the review. This resulted in the retrieval of many irrelevant documents, with obvious resource implications. The importance of informal sources was highlighted in Review 2, where nearly a quarter of the references included in the review were found by personal communication.

Management of references With large numbers of references to assess, there is potential for confusion and error. We used Reference Manager® to organise the results of the literature searches and other potentially relevant references. One team member managed the database to ensure consistency of data entry. Records were assigned a unique identity number, permitting the tracking of documents. We agreed on keywords to record decisions or comments in the user-defined fields, which facilitated searching the database.

Data extraction Microsoft Access® was used for the data extraction, it permits flexibility of data manipulation and is able to run queries. We detailed all data, findings and concepts that related to the central research question, to avoid the need to re-visit the primary research documents at the synthesis stage. It is important to record page numbers in books or reports for easy checking, and to be clear whether the information recorded is a paraphrase or quotation.

Synthesis Research synthesis consolidates findings from primary studies to help inform policy and practice, and helps to identify the research questions for future research. There are different ways of collating the evidence from primary studies, essentially reflecting the type of data collected:

- Statistical meta-analysis is used to summarise quantitative results from randomised control trials, where studies are sufficiently similar.

- Narrative synthesis is used for qualitative data and for quantitative data if the studies are dissimilar.

- A combination of narrative and statistical approaches may be used.

Our narrative approach involved collating the data from the studies included in each review to present an overview of the collected material under different sub-headings, supported by a commentary. One of the outputs of the synthesis of Review 2 took the form of a refined theoretical model identifying barriers to access to health care specifically relating to carers.

Consultation

All three reviews were enhanced by holding consultation exercises with relevant stakeholders, including representatives from national statutory and voluntary bodies, practitioners from local organisations, and carers. In Review 1, for example, there were important differences in the way contributors defined the effectiveness and cost-effectiveness of services, compared with definitions used in the literature.

Methodological Issues

Assessing effectiveness Defining what 'effectiveness' means in the assessment of support services for carers is a key methodological challenge. The 'perspective' of the analysis determines whose benefits are assessed. Policy makers, service providers, carers, care recipients or society may all benefit from an intervention. If we want to assess benefits for two or more of these groups, we need to decide how to 'add up' the benefits, including any 'dis-benefits'.

There are issues about *how* to measure benefit. Most studies included in the three reviews used off-the-shelf instruments to evaluate the effectiveness of support services, assessing carer burden, stress, coping, and physical, mental or emotional health. When applied to carer support services, the sensitivity of these instruments to detect change is unclear, as is the extent to which they reflect carers', or care recipients', priorities. Review 3 found that the effectiveness of respite care for carers for people with dementia was limited. In contrast, there was considerable qualitative evidence from carers endorsing the beneficial effects of respite. This inconsistency underlines concerns about the sensitivity and validity of the measures of effectiveness.

Service utilisation rates can also serve as outcome measures, but these too have limitations. Low levels of utilisation do not necessarily mean the service is of little benefit. For instance, a consultation with carers in Review 1 revealed that they benefited from knowing that a telephone help-line was there should they need it: the service effectively acted as a 'safety net'.

Assessing cost-effectiveness

The difficulties in assessing effectiveness impact on cost-effectiveness analysis: even if the costs of support services can be reliably estimated, without valid measures of an effect, cost-effectiveness remains unclear. Many economic evaluations of support services were conducted outside the UK. Where the comparison intervention – typically, 'standard' or ordinary, mainstream care – was poorly described in these studies, the findings were difficult to interpret for the UK setting.

Time horizons

The time points at which studies assess the effectiveness and cost-effectiveness of an intervention can affect findings. Studies with an inadequate follow up may not detect longer-term effects, biasing findings in favour of interventions with short-term benefits.

What counts as 'evidence'

The reviews focussed on the evidence from good empirical research. Reflecting current thinking about the value of knowledge derived from

Box 2: Quality Criteria Appraisal Tool			
1	Question	Is the research question clear?	E
2	Theoretical perspective	Is the theoretical or ideological perspective of the author (or funder) explicit, and has this influenced the study design, methods or research findings?	D
3	Study design	Is the study design appropriate to answer the question?	E
4	Context	Is the context or setting adequately described?	D
5	Sampling	*(Qualitative)* Is the sample adequate to explore the range of subjects and settings, and has it been drawn from an appropriate population? *(Quantitative)* Is the sample size adequate for the analysis used and has it been drawn from an appropriate population?	E
6	Data collection	Was the data collection adequately described and rigorously conducted to ensure confidence in the findings?	E
7	Data analysis	Is there evidence that the data analysis was rigorously conducted to ensure confidence in the findings?	E
8	Reflexivity	Are the findings substantiated by the data and has consideration been given to any limitations of the methods or data that may have affected the results?	D
9	General-isability	Do any claims to generalisability follow logically, theoretically and statistically from the data?	D
10	Ethics	Have ethical issues been addressed and confidentiality respected?	D*

E=Essential; D=Desirable; * May be 'Essential' in some (sensitive) fields of study.

Source: Croucher K., Quilgars D., Wallace A., Baldwin, S. and Mather, L. (2003) *Paying the Mortgage? A Systematic Review of Safety Nets for Homeowners.* York: Department of Social Policy and Social Work, University of York.

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Box 3: 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 Control Trial (RCT) (e.g. Systematic Reviews from Cochrane or Centre for Reviews and Dissemination)
A2	Other systematic and high quality reviews which synthesise studies
B1	Individual RCTs
B2	Individual experimental/intervention non-randomised 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)

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

different sources, we also included material from practitioners, carers and relevant voluntary organisations.

Assessing the robustness of evidence Reviews 2 and 3 addressed the issue of how confident we could be in the evidence found. We appraised the quality of all studies using a generic set of questions, designed to ensure they were 'good enough' studies upon which to base policy decisions *(Box 2)*. In addition, we used a typology of study designs, adapted from the National Service Framework for Older People, as a classification device, although it was not presented as a traditional hierarchy of evidence *(Box 3)*.

Further research In all three reviews, the gaps in the evidence base highlighted the need for well-controlled studies that appropriately combined quantitative and qualitative methods to assess effectiveness and cost-effectiveness. It was also disappointingly clear that many innovative projects reported in the literature are yet to be evaluated.

In conclusion, our experiences from undertaking these three reviews have highlighted that good managerial and methodological systems are vital. Regular and good communication within the team can help to address the intellectual challenges that are encountered. Reviews need to be adequately resourced and undertaken by a multidisciplinary team with expertise in the area under review.

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