

Making a Break

Developing methods for measuring the impact of Respite Services

**Making a Break: Developing methods for
measuring the impact of respite services**

**Rosemary A. Chesson
Catherine E Westwood**

June 2004

Contents

Acknowledgements

Summary

Background

Policy Context	1
Key Issues	2
The Study	7

Project Design

Literature Review	8
Qualitative Study	10

Findings

Literature Search & Review	15
The Grey Literature	15
Peer-reviewed Publications	19
Overview of Review	28
Interview Study	29
Recruitment	29
Study Participants	30
Caring Relationships	31
Participants Health & Social Support	34
Health	34
Social Support	39
Knowledge of Respite	41
Use of Respite	45
Overview	49
Case Studies	50

Discussion & Conclusion 65

Research Design	65
Caring Relationships & Outcome Measures	67
Partnership Working	69
Main Implications & Issues	70
Conclusion	73

References

Appendix

Acknowledgements

We wish to acknowledge the contributions of the Project Advisory Group (John Leggate, Elizabeth McDade, Pat Robbins and Margaret Ross); all participants, without whose help this work could not have been undertaken; all health and social care workers who distributed our leaflets; Susan Barnett who helped with compiling the quotations; Jaqui Stewart who collated, and produced this report and Lindsay Mathers who designed the report cover.

**Rosemary Chesson
Catherine Westwood**

June 2004

SUMMARY

Background: This study took place during a period of rapid social policy development within Scotland, thus providing an impetus for reviewing respite services. While comprehensive surveys of respite provision have been undertaken, there have been few attempts to measure the outcome of respite for care recipients and carers living in the UK.

Study aims: The main aims were to (1) investigate the role of respite care for: children with complex needs and their carers; adults with learning disabilities and their carers; people with multiple sclerosis and their carers; people with schizophrenia and their carers and frail elderly people (excluding those with Alzheimer disease) and their carers; (2) identify the most appropriate outcome measures for use with the above groups in the evaluation of respite care and (3) foster partnership working between university researchers and voluntary sector organisations.

Study design: The project included a review of grey and published literature and an interview study.

Literature review: A wide range of databases were searched including Medline, Cinahl, BIDS, ASSIA, British Nursing Index and SIGLE. Key terms applied were respite, short-breaks, carers, caregivers in conjunction with effects, effectiveness, outcome, outcome measure together with relevant descriptors for the care groups included in the study. The search strategy followed the recommendations of the NHS Centre for Reviews.

Qualitative study: The main method of data collection was semi-structured interviews with carers and care recipients who volunteered to participate in the research. Prior to interview participants filled in a checklist and during the interview completed the Nottingham Health profile, the Hospital Anxiety and Depression Scale and the Social Support Questionnaire as well as describing their experience of respite and its impact on them and their families. Interviews were audio-recorded (given consent), transcribed in full. Data analysis followed the process as described by Miles and Huberman (1994). Case studies were constructed if written consent was obtained and biographical details changed to as to maintain confidentiality.

Findings: *Literature review:* Difficulties were experienced in accessing literature and major flaws were found in studies included in the grey literature. One of the main findings of the review was the flexibility of respite definitions and the very wide range of services included. Methodological weaknesses were evident in many of the articles reviewed. Robust evidence on the effects of respite care was

lacking. The majority of research which focused on effects related to short-term provision. There was a paucity of research relating to people with multiple sclerosis and mental health problems.

Interview study: Sixty people participated in the study, including 20 men and 40 women, of whom nine and 27 of the men and women respectively were carers. Seventeen 'paired' interviews were undertaken. Four major roles for respite were revealed across care groups during the interviews, which we categorised as follows: 'important for when I won't be here any more'; 'enables a crisis to be overcome'; 'helping to overcome carer physical/emotional exhaustion' and 'providing time to spend with other family members'. In addition, interviews highlighted confusion regarding '*what counts as respite and what doesn't*'. Most support networks were small but not all participants had used respite and residential care was the most commonly used. Finally the qualitative study highlighted diversity in a number of respects including the range in different types of caring relationships; in the nature of provision and usage and in home circumstances.

Discussion/conclusion: The study demonstrated the complexity of undertaking research on respite care, the value of including care recipients and carers, the need to investigate respite usage over a lengthy time period, and the importance of the individual's perceptions of their circumstances. Partnership working is recommended in order to increase understanding of the role of research. It is concluded that it is not possible to propose a single measure, or even basket of measures, to demonstrate the effectiveness of respite care. Our interviews indicated above all else that an holistic approach to respite care is required.

BACKGROUND

Policy Context

Government policy regarding respite has evolved over the last 15 years. Key policy documents have been the NHS and Community Care Act, 1990; the Carers (Recognition and Services) Act, 1995; the Community Care in Scotland: Guidance on Respite Care (Circular SOSWSG 10/96); the National Strategy for Carers in Scotland, 1999 and the Community Care & Health (Scotland) Act, 2002. All of these paved the way for more support to be offered to people with disabilities and carers, thus providing an impetus for reviewing respite services. Important to note is that the study reported here, took place during a phase of rapid social policy development within Scotland.

In the past, emphasis has been placed on the provision of respite for the benefit of the carer (McNally et al, 1999). Now it is more widely recognised that respite is equally important for the cared for person and should be a positive experience for them, as well as their carer (The Scottish Office Social Work Services Group, 1996). This has led to increasing use of the term 'short breaks' which, it has been suggested, avoids the implication that respite is primarily to reduce the burden of care for the carer and is crisis orientated (Scottish Executive, 2000). In this report, nevertheless, we have used the term respite care to avoid some of the confusion around 'short breaks' (Chesson, 2001) and overcome the inadequacy of 'short breaks' as a key term for electronic database searching.

Over the last decade a growing number of new and more imaginative respite initiatives have taken place. Many of these seek to enhance and develop the quality of people's lives and support the caring relationship (Lothian Short Breaks and Breaks from Caring Group, 2001). It is more widely acknowledged than previously that respite can be provided within or outwith an individual's home and

may extend from a few hours to a few weeks. Recent definitions of respite reflect this and differ from those of the past which include overnight provision as a criteria (Robinson, 2003).

It is vital for future policy that the evidence base for respite is examined. In this report we present the evidence that we have discovered. Firstly, we outline some of the key issues. In chapter two we describe the methods used in determining what is known about the effects of respite. In the following chapter we present the evidence from our literature review and interview study and in doing so revisit the issues outlined in this introduction. Finally we discuss our findings, set out the conclusions reached and consider the implications for practice.

Key issues

Knowledge of respite: Research on respite care is not easy to access. The overwhelming majority of research relating to respite has been undertaken in the USA, most dating from the 1980s. By far the greatest number of publications concern respite services developed as part of services for people with Alzheimer's disease, followed by those relating to children with developmental disorders. Publications focusing on respite for people with physical disabilities and non-dementia related mental health problems are difficult to find, together with those on palliative care.

Although there is a growing volume of work on respite, a coherent body of knowledge is lacking. Published work covers a wide range of specialities, and is published in medical, nursing, psychology and social work journals. Differences in definitions and terminology between the USA and the UK are major obstacles to increasing understanding and to the transferability of findings. Notably in the USA respite care not only encompasses day care but may include also provision referred to in the UK as home care services (Donaghy, 1999). More commonly in the USA respite is embedded within the provision of community services

located on a continuum of long term care (Zarit et al, 1990). In particular, in the USA, one of the main areas for research has been to determine the extent to which respite services may delay institutionalisation for older people (Lawton, et al, 1991; Kosloski & Montgomery, 1995; Gottlieb & Johnson, 1995).

Role of respite: To some considerable extent the primary interest for researchers has been the carer rather than the person with health problems who requires care. Despite this emphasis on carers, it is only recently that their own perspectives on respite have been sought (Strang, 2000). Specifically regarding services for people with Alzheimer's disease it has been observed that 'there is debate over whether the primary target of formal services is the patient with dementia or the caregiver' (Zarit et al, 1999). But Zarit and colleagues argue that a service which benefits one member of the caregiving dyad benefits 'the other as well' (Zarit et al, 1999). Caregivers are seen to obtain 'relief' while 'their relative' is assisted to live in the community (Cox, 1997). Cowen and Reed reflecting this view, distinguish between primary and secondary services of respite as follows:

Primary respite care: services are regarded as providing relief to the family (on primary care giving). These are seen to offer support relating to the 'intensive demands of the child/family members with disabilities'.

Secondary respite services: are seen as addressing the needs of individuals with disabilities and may include educational or vocational training programmes and support services, such as speech, occupational or physical therapy (Cowen & Reed, 2001).

It is clear from the literature that respite services are regarded as performing a wide range of functions, although in reports primary aims are seldom identified. Few authors examine how respite might act as an interventional and preventative service. This is most likely to be considered, however, in research

relating to children. Researchers in Canada, for instance regard respite child care programmes as 'part of a comprehensive approach to early intervention and child maltreatment prevention efforts for 'at risk' and 'special needs' children (Cowen & Reed, 2001).

Respite provision: Despite greater awareness of people's needs, respite services have developed on an ad hoc basis across Scotland. In particular, provision has been patchy, regarding both the type of respite and client group (Lindsay et al, 1993). Although local authorities are expected to address problems relating to respite, few have in place coherent strategies (Mitchell & Chesson, 2002). Today, there continues to be considerable variation in provision. But it is widely believed that there is too little respite for too few people. Yet, the demand for respite care is likely to increase over coming years, relating to a number of factors including: an increasing population of older people; a growth in the number of people with disabilities and long standing illness; more care in the community; increasing recognition of the needs of carers and an ever increasing dependence on unpaid carers to provide care.

Robinson and Stalker's Department of Health survey, undertaken in the late 1980s, raised many issues to be subsequently identified in later studies, not only relating to children but other care groups as well. Thus, this work is considered in more detail here.

The Robinson & Stalker 1989 Survey: The main aims of the study were to describe the nature and context of respite care services available for young people (up to 20 years), including in hospitals, hostels and family based schemes, in three local authority areas (Croydon, Sheffield and Somerset). The experiences of 586 children and young people were documented and the main conclusions from the study were:

- that there was poor record keeping of client information and of services received, as well as non-standardised recording and classification of use;
- approximately 1 in 5 children were receiving services from more than one provider;
- 43% of families indicated the need for more services, mostly respite due to current inadequacies of provision;
- 20% were highly critical of current respite provision and there was a lack of knowledge of respite;
- respite was seen as beneficial to families and the young person concerned;
- barriers to respite uptake were identified as concerns over the disruption of the child's routine and fear of long term care.

(Robinson & Stalker, 1989)

A frequently expressed view today is that the lack of reliable statistical data regarding respite is an obstacle to policy development, not least because it inhibits financial planning. Thus of considerable interest is the work of Lindsey and colleagues in Scotland in the mid 1990s. Although *The Patchwork Quilt* did not lead to a national policy on respite it did underpin the production of *The Scottish Office Social Work Services Group Guidance on Respite Care* in 1996.

The Patchwork Quilt: Lindsay et al's work was funded by the Scottish Office to determine the range, volume, style and costs of respite care services in Scotland. The investigation covered respite provided away from home through to domiciliary services. Day care was not included. The report focused on five main care groups: older people; people with dementia; people with mental health problems; adults and children with physical disabilities. The overwhelming picture which emerged was of considerable variation in provision. Specific findings were that:

- nearly 800 residential establishments offered respite care, with 320 having beds designated for that purpose;
- eighty-six hospital units who responded provided respite care;
- of nearly 800 residential services, 80% were for elderly people and 14% for people with learning disabilities;
- only 4% of residential services were 'respite only' care;
- while it was difficult to estimate the number of people receiving respite care in hospital it was concluded that a substantial number of people (perhaps 5-6000) received this service;
- people with physical disabilities tended to receive respite care alongside other groups with whom they have little in common, in hospital or nursing homes. The number of places was very limited and there were very few specialist services;
- information on the costs of respite care was very limited and sources of funding vary considerably. Insecurity of funding was seen to inhibit developments;
- unit costs of residential care were significantly higher than for permanent care.

(Lindsay et al, 1993)

There is some evidence, moreover, that these patterns of provision persist today. For example a study of residential respite provision in Aberdeen found that only a minority of care homes had designated respite places and that provision was predominantly for older people and individuals with learning disabilities (Mitchell & Chesson, 2002). This study, therefore, well demonstrated the overall low levels of provision within one Scottish city.

The study

It is important that our work is seen within the context of the provision of respite in Scotland, even though we focus on specific groups of users, including some who have been significantly neglected by providers and researchers alike. Concomitantly, we did not seek to review all of the respite literature, but rather restricted our consideration to the aims set out below.

Study Aims

The main aims of the study were to:

- 1) investigate the role of respite care for:
 - (a) children with complex needs and their carers
 - (b) adults with learning disabilities and their carers
 - (c) people with multiple sclerosis and their carers
 - (d) people with schizophrenia and their carers
 - (e) frail elderly people (excluding those with Alzheimer disease) and their carers
- 2) identify the most appropriate outcome measures for use with the above groups in the evaluation of respite care.
- 3) foster partnership working between university researchers and voluntary sector organisations, reflecting the aims of the Community Fund Health and Social Care Research Programme

The overall project approach, therefore, sought to meet the above aims. Details of how this was achieved are provided in the following section.

PROJECT DESIGN

The design included both primary and secondary studies, namely a qualitative study and a review of grey and published literature.

Literature Review

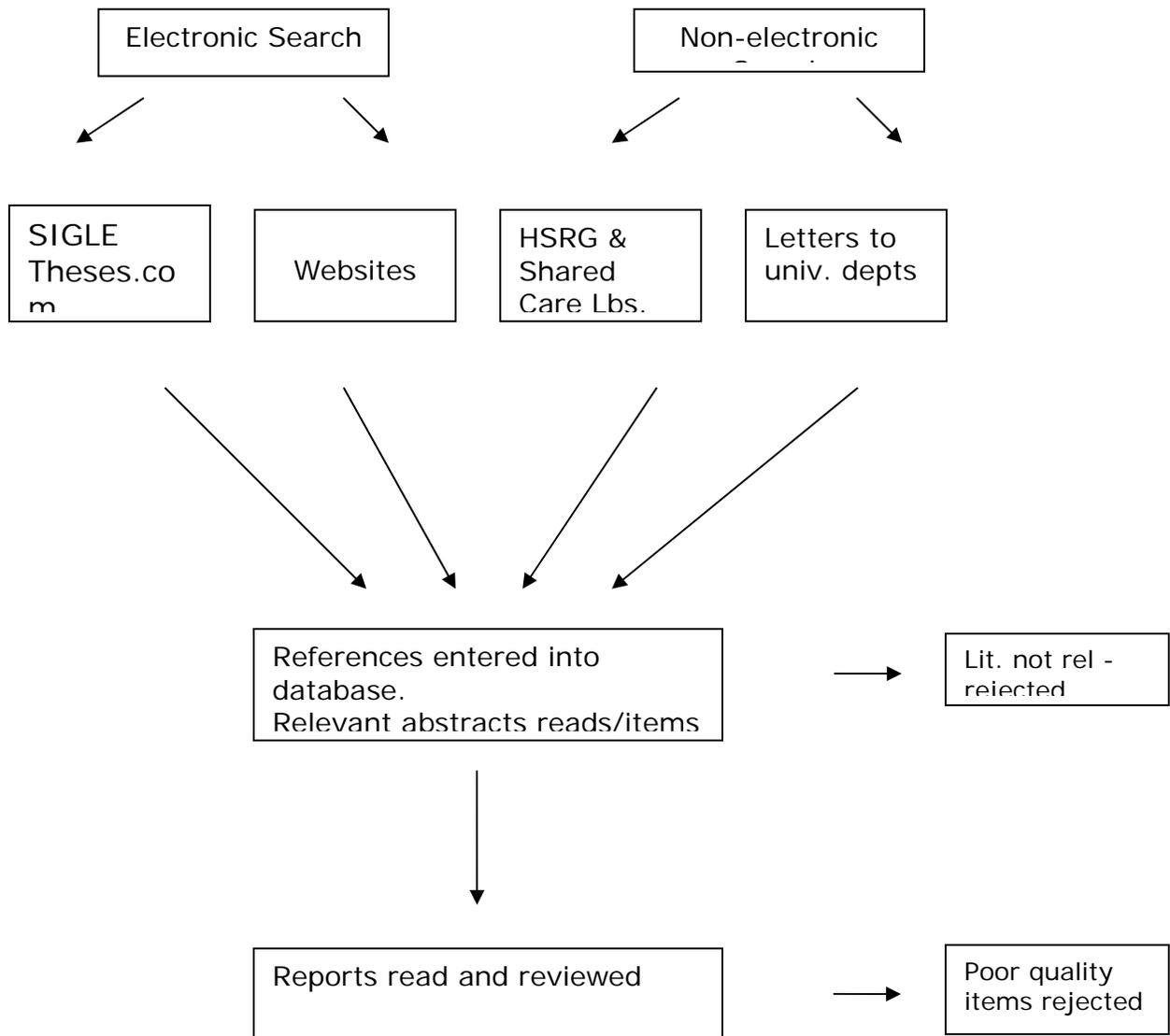
Grey literature

It was decided to include grey literature (material which is semi-published, not formally published or available commercially) in the review because it was believed that there were a significant number of unpublished evaluations of respite. However, these would need critical appraisal since they had not been subject to peer review. While the electronic database System for Information on Grey Literature (SIGLE) was used together with Index to Theses (Theses.com) it was recognised that these would provide only partial coverage of potentially relevant studies. Letters were sent, therefore, to university departments requesting information on any relevant reports. In addition, voluntary agencies were contacted and items were accessed through Shared Care Scotland's library. The search strategy for the grey literature is shown in Figure 1.

Published literature

For the purpose of searching for published work a wide range of databases were used (box 1). The search was limited to English language publications. Key terms applied were respite, short-breaks, carers, caregivers in conjunction with effects, effectiveness, outcome, outcome measures together with relevant descriptors for the care groups included in the study. The search strategy followed the recommendations of the NHS Centre for Reviews at York and Dissemination (2001).

Figure 1: Search Strategy for grey literature



Box 1: Main databases searched

MEDLINE 1989-2000	CINAHL 1989-2000 *
BIDS 1995-2000	CAREDATA 1990-2000
ASSIA 1990-2000	HEBS
NISW 1989 – 2000	SOSIG 1989-2000
British Nursing Index 1990-2000 *	Cochrane Collaboration

** updated June 2003*

Qualitative study

Approach

A qualitative approach was adopted for the study because of the difficulties in respite definition and service identification and the paucity of research in the area. It was decided to undertake the work across Scotland, in order to reflect local variation which Lindsay and her colleagues had documented in the early 90s. Work was focused on three areas - Aberdeen City; the Highlands and Greater Glasgow, extending to South Lanarkshire and Renfrewshire. These locations provided for a mix of rural, urban and inner-city service users as well as different local authorities with differing policies. In order to undertake the research Ethical Approval was obtained from Grampian Research Ethics Committee, Highland Health Board Ethics Committee and Argyll and Clyde Local Research Ethics Committee.

Data collection

The main method of data collection was semi-structured interviews with carers and care recipients who volunteered to participate in the research. Prior to recruitment commencing, networking meetings were held in Lochaber, Inverness, Renfrewshire and South Lanarkshire. Regular contact was maintained throughout the project with key individuals (for example user involvement workers) and key organisations, such as Age Concern, the MS Society and National Schizophrenia Fellowship. During the project a range of other strategies were developed with the Project Advisory Group so as to encourage participation. These included visits to day centres and luncheon clubs and parents' evenings.

Leaflets inviting participation were distributed widely through both health and social care staff and members of voluntary organisations. Information was developed for professionals and service users and leaflets were customised for the needs of adults and children and pictorial versions were available for people with learning disabilities. Initially we sought pairs of participants (carer and care recipient) and our approach was first of all to recruit through one member of the pair. However, difficulties were experienced in recruiting so as the project progressed we came to include singleton interviews.

The Interviews: Following discussions with respite providers and users interviews were held in people's own homes, unless an alternative was requested. Separate interviews were held with the carer and care recipient, and included the following elements:

- 1) completion and discussion of a respite checklist (Appendix 1). If possible this was completed prior to interview and formed the basis of discussion during the interview. The checklist provided participants with an indication of the nature of the topics to be covered and enabled them to reflect on their experiences prior to the interview.

- 2) the interview schedule. In addition to discussion of the checklist, the interviews provided the opportunity for the interviewee to explore experiences of respite and the effects it had had on them and their families.
- 3) completion of three pre-existing validated measures – the Nottingham Health Profile (NHP), the Hospital Anxiety and Depression Scale (HADS) and the Social Support Questionnaire (SSQ). The latter instruments were selected in order to provide data on study participants' health and the extent to which informal support networks were available to the carer and cared for.

The Nottingham Health Profile (NHP): The NHP is a self administered questionnaire designed to measure perceived health problems and the extent to which such problems affect daily activities. Six areas are covered in the tool namely: sleep; energy; emotional reactions; social isolation; physical mobility; and pain.

The Hospital Anxiety and Depression Scale (HADS): this comprises two subscales, one measuring anxiety (A-scale) and the other depression (D-scale) which are scored separately.

A-Scale: Scores reflect a state of generalised anxiety and are not necessarily focused on any specific situation. It should be noted that the manifold somatic symptoms of anxiety state are not reflected in the A-Scale.

D-Scale: This scale focuses largely, though not entirely on, the state of loss of interest and diminished pleasure response (rather than other states such as grief and pessimism). A persistently high score on this scale may be indicative of clinical depression. The separation of the items into two subscales is based on their correlation to independent assessment.

The Social Support Questionnaire (SSQ): This seeks to 'quantify the availability of and satisfaction with social support' (Sarason et al, 1983). The questionnaire focuses on two central elements of the concept: the perception that there are sufficient people available to help in times of need and the degree of satisfaction with the support available (Sarason et al 1983, Sarason et al 1985).

If during the interview participants appeared to become fatigued they were asked if they wished for the remainder of the interview to be undertaken at a later date.

All interviews were audio-taped with the written consent of participants. All tapes were transcribed in full.

Pilot interviews: Interviews were undertaken in Tayside (with approval from the Tayside Committee on Medical Research Ethics). The pilot indicated that it was possible for some participants to complete the validated instruments and confirmed that the Respite Checklist was helpful in providing an overview of participants' experience of respite. These interviews demonstrated that interviews could be completed in approximately 60 minutes.

Data analysis

The approach to data analysis followed the procedures as described by Miles and Huberman (1994). Transcriptions were read by the authors and the main themes emerging were identified. Blocks of text relating to themes were coded and any sub themes revealed were categorised. Transcriptions were then reviewed for any omissions in the selection and identification of themes. All quotations from interviews were then placed within the thematic framework. All interviewees were identified by alphabetical identifiers and these have been used in this report.

Scores on the NHP, HADS and SSQ were entered into SPSS-PC and simple descriptive statistics were produced.

Case studies were constructed so as to reflect the context in which views were expressed and in particular were to provide an overall picture of home circumstances, life events and to demonstrate the effects of respite, (where this had been received). Written consent was sought from all the participants included in the case studies presented in the report. Biographical and some other details such as regarding geographical location have been changed in order to maintain confidentiality.

The trustworthiness of the data and interpretations were established in a variety of ways . Triangulation was used in the case of paired interviews and responses given to the Respite Checklist and views expressed at interview were compared both for paired and singleton interviews. Observational data acquired in the course of recruitment also contributed to assessing the trustworthiness of the data.

FINDINGS

Literature search and review

The grey literature

The grey literature was time consuming to access and some of our strategies had limited success. For example, replies were not forthcoming from university departments regarding past or current respite research. Although SIGLE was used, several items obtained through other routes were not included on this database. The main source of unpublished material we used was Shared Care Scotland's own library. However, many of the items scanned for possible inclusion took the form of information for carers on respite provision, information on referral or descriptions of available services. Another significant source of unpublished work was social work and voluntary agency staff who had a strong interest in respite. 'Word of mouth' and 'memory' became important search 'tools'.

Internal reports: Overall our search yielded a low volume of usable items. Sometimes 'reports' were primarily proposals for seeking funding for respite services. Often basic bibliographic data, such as date of the report, were missing. The majority of items obtained were one-off in-house small scale surveys. Table 1 gives examples of the kind of reports considered.

Not all the items obtained, read and reviewed are presented here for the following reasons:

1. few reports considered the effects or outcomes of respite care, rather they focussed on client need for respite, demand for new provision or satisfaction with services provided;
2. significant details regarding the studies were missing;
3. flaws in design were evident, for example, regarding the response rates to questionnaire surveys.

Table 1: Examples of unpublished reports obtained

Author(s)	Sponsor	Date	Main Aim	Method	Results
Callaghan Colquhoun	Social Work Services, Central Regional Council	1994	'To sound views' of people who had referred clients to Penumbra.	20 q'aires distributed to each individual who had referred a client for RC since the service's inception. This included SW staff, CPNs, vol. orgs and other health staff (103 people had taken advantage of respite at Cairdeas House between Nov 1992 & March 1994)	No information provided on response rate or respondents. All respondents confirmed that the referred clients had benefited from the experience. Most emphasised the positive approaches of (1) companionship; (2) new experiences; (3) relief from domestic situation; (4) choice of activities; (5) support from staff. Other aspects noted were: (1) reduction in symptomology; (2) increased ability to cope with the stresses of everyday life; (3) allowing time and space to put problems in perspective. 100% of respondents stated that they would refer other clients.
Griffin	Shared Care Scotland (grant in aid from Scottish Office)	1994	To undertake an Investigation into the feasibility of devel. new volunteer schemes for respite care for families of children with special needs.	Information leaflets sent out to head teachers, HVs, etc for distribution to parents/ guardians know or assumed to be in research category. Interviews with parents/guardians.	45 responses were received. 6 declined and 39 parents interviewed. 28 of 39 felt that volunteer involvement in respite care was worthwhile. Often repeated comment was 'lack of detailed information about type of respite care the voluntary services were offering.' 22/39 were currently using or wishing to access respite. A frequent comment was re desirability of having a range of respite care options from which to choose.
Stobie	Joint Community Care Planning Group for Physical Disability (Aberdeen)	1999	To investigate respite provision for people with a physical disability	Survey piloted by Aberdeen Action on Disability. Questionnaire survey of 171 people with disability and 165 carers	13% of people with disabilities and 17% of carers returned questionnaires

However, common to the reports were: difficulties in identifying the study population; achieving participation and the small number of people using respite services.

Theses: The search undertaken on Index to Theses (theses.com) revealed eight items from a collection of 457,024 theses. Two were excluded following abstracts being read because either the primary focus was on nursing needs or there was little reference to respite care. In one further case (Smith) no further information could be obtained. Details of the six thesis are given in Table 2 overleaf.

One of the earliest thesis of greatest relevance to us and was by Stalker, submitted in 1987. The aims of the study were to evaluate Share-the-Care, Lothian's family based respite care scheme for children 'with a mental handicap' and assess the impact on the lives of children, parents and carers. One of the main findings was that the scheme reduced levels of parental stress and strengthened their ability to cope (based on interviews with carers, questionnaires completed by referring agencies and data collected from agency records). However, those who originally presented as experiencing relatively little stress were most likely to receive services and were regarded as using them with the least difficulty. Most parents identified a range of benefits to the child from involvement in the scheme, although homesickness among children emerged as an important issue.

Interesting to note is that Stalker has subsequently published extensively on respite and together with Robinson has made a significant contribution to respite research. Nolan, although more widely recognised for his work regarding carers, has also become a much cited author regarding respite care. Thus in both cases work relating to respite may be accessed through publication databases.

Table 2: UK theses relating to respite care (1980 – 2003)

Author	Date	Title	Univ/Qual
Stalker	1987	An evaluation of a family-based respite care scheme for children with mental handicap	Edinburgh, PhD
Smith	1988	Caring for carers: an evaluation of a domiciliary respite care scheme	Durham, MA
Nolan	1991	Timeshare beds: a pluralistic evaluation of rota bed systems in continuing care hospitals (beds providing respite care to carers and 'dependent' elderly).	Bangor, Wales, PhD
Kitching	1992	The use of respite services in North Staffordshire by families with a member with a mental handicap.	Keele, MA
Lane	2002	An exploration of the health and social care needs and experiences of family carers of older people.	Ulster, PhD
Maynard	2000	An exploratory study of the needs of children with life-threatening illnesses and their families and the potential role of community children's nursing.	London, PhD

Peer-reviewed publications

The majority of items accessed were retrieved through the key term 'respite' and described research undertaken in the USA and published in American journals. We decided to exclude articles which primarily discussed fostering, although we recognise that there is an overlap between fostering and respite care. For example, the guidance provided by the British Association of Adoption and Fostering Parents states that 'there are a number of specialist fostering schemes which your local authority or a neighbouring one may run. For example, some children need very temporary care but on a regular basis, perhaps one or two weekends a month. This is often called 'respite care' (Lord, 2002).

A major challenge for us was to decide which articles to include. Articles describing rehabilitation programmes were excluded (for example, Pomeroy et al, 1999) but others reporting on day care, including attendance at day hospitals, were considered for inclusion. In fact, one of the main findings for the review was the flexibility of respite definitions and the very wide range of services included. Particular difficulties were posed by holiday respite and respite care as part of palliative care provision.

Following the retrieval and reading of papers, we identified 40 papers related to the aims of our project. Five of these were literature reviews and table 3 provides information on their scope, aims and main conclusions. A fifth (Horsburgh et al, 2002) is excluded as it focuses primarily on New Zealand literature.

Literature reviews: The majority of articles examined in the reviews related to North American research and focus primarily on the carers of older people (although children were the second most commonly considered group by McNally et al 1999). Overall effects were found difficult to discover. For instance one of the early studies by Lawton et al in the USA, found no differences between the experimental group (in receipt of respite) and controls with regard to: (1) the risk of death of the elderly person; (2) the risk of institutionalisation of the elderly

Table 3: Published reviews of respite literature

Author	Date	Databases searched	Focus of review	Results/Conclusions
McNally et al	1999	Psychlit, ASSIA, Medline	Assessing the effects of respite intervention on informal carers	29 studies identified. 'No firm conclusions may be drawn regarding the effectiveness of the various types of respite care, although there is a suggestion that in-patient intervention may be more effective'.
Hanson et al	1999	Age.Info, ASSIA, BIDS, ISI, Cinahl, Embase, Medline	Respite care for frail older people. Examines definitions, locations of care and user needs. (part of wider study regarding respite for older people).	Effects of institutional respite care on caregivers is largely inconclusive
Zarit et al	1999	Not stated	Effects of community based services in relieving stress on family caregivers and on delaying/preventing the institutionalisation of frail elders.	Approx 26 studies identified from references section Paper. There are few empirical studies overall. Reported benefits 'typically are modest'. Little evidence to suggest that community services delay placement.
Ingleton et al	2003	Web of Science, Medline, Cinahl, Cocherane, ASSIA	Adult respite care in specialist palliative care. Considers definitions and assumptions that underpin term respite and its impact on outcome of carers in palliative care contexts.	28 studies relating to specialist palliative care. Review did not identify any empirical studies assessing the effects of respite provided by specialist palliative care services on carer outcome. Insufficient evidence to draw conclusions re efficacy of offering respite care to support carers of patients with advanced disease.

person; and (3) the well-being of the caregiver. In addition, family caregivers in the experimental group showed no improvement in mental health status, regardless of the amount of respite services they received (Lawton et al, 1989). However McNally et al (1999) suggested that more recent studies (from 1992), are more likely to show benefits from respite care than those of earlier years (1985-1999).

Broadly similar issues emerged across all four reviews including: (a) problems with terminology; (b) the nature of respite services and their interaction with other services and sources of informal support and (c) methodological weaknesses.

- a) *Problems with Terminology*: Both Tester (1999) and Donaghy (1999) in commenting on Zarit et al's review draw attention to the fact that definitions and terminology vary between countries. Tester (1999) cautions that all concerned need to understand what is being compared when terms such as respite care and caregiver are used. Donaghy (1999) specifically points out that respite care in the USA 'appears to equate with home care in the UK'.
- b) *Nature of respite services*: Ingleton et al (2003) draw attention to the situation that respite as a service offers 'an array of possibilities in the context of palliative care, ranging from in-patient care to day care to home-based care.' McNally et al also note that the duration and frequency of respite care differed widely in studies and distinguish between those which evaluate 'one dose' and those 'a course'. Thus it is argued that 'small accounts of help will make a small difference' (Zarit et al, 1999). Clearly this is likely to have a significant impact on effectiveness since as Zarit and colleagues argue 'just as it would be poor science to test the effects of a new medication while using a sub-therapeutic dosage, it makes no sense to evaluate a service programme that does not give adequate help' (Zarit et al, 1999: 175).

Even though the reviews make explicit the range of services considered as respite, little attention is paid to whether they *should* be so categorised and thereby included in the review. For example nearly a third of the papers considered by McNally and colleagues in their review refer to day care, and in one case, day hospital care. Where respite is distinguished from other services, it often described especially in the US as forming part of a community care service programme, yet little attempt is made to isolate the effects of other services. Overall there is little consideration or control for 'contextual issues' (Donaghy, 1999).

Wider social networks receive scant attention. Indeed McNally et al conclude that the influence of social activity or support on the effectiveness of respite has never been evaluated (McNally et al, 1999).

- c) *Methodological weaknesses*: All reviewers refer to the methodological weaknesses of many of the studies reviewed, including the size of samples, lack of control of variables and insensitive or inappropriate outcome measures. Zarit et al, 1999, for example observe that in-home respite 'is not designed as a treatment for a caregiver's depression.' Other issues raised include: the relationship between respite provision and the timing of outcome assessment; the failure to consider the relationship between carers and care recipient and the 'selective' nature of samples since not all those who might benefit from services use them.

Primary Studies: Eighteen of the 29 studies reviewed by McNally et al 1999 relate to the care groups selected for this study. However, only two (Homer & Gilleard, 1994; Stephenson et al 1995) were undertaken in the UK.

Subsequent searching for articles published after the McNally et al review in 1999 revealed a broadening of interest, as well as a focus on 'new' care groups. For example, regarding the former, Malonebeach et al (1999) in the USA

examined the use of video as a means to provide respite for carers of people with dementia and Brown et al (2000) reported on a survey of physicians (463; 64.3% response rate) regarding their perceptions of respite availability. Relating to a widening of interest by researchers, Strang et al 2002 considered carers' views about their experience of respite during home based family caregiving for persons with advanced cancer and Stajduhar et al (2002) undertook an evaluation of a respite service for persons living with AIDS.

Notable is the increasing volume of respite research illustrated by the growth of interest in the UK, as indicated in table 4. However, recent work also has methodological flaws so that conclusions need to be treated with caution. For instance only 18.6% of carers contacted participated in Nicoll et al's research reported in 2001.

Consistently over the years children and families have formed a significant element within respite research, as illustrated by the North American studies listed in table 5. Yet Horsburgh et al (2002) from a review focusing predominantly on New Zealand literature, argue that little attention has been given to the area of paediatric respite either internationally or in New Zealand. But new challenges have arisen with changes in care delivery. The complexity of both defining complex health needs and identifying appropriate respite care, especially for 'technology dependent children' is well explored by Miller (2002). Hoare and colleagues highlight the difficulties of measuring the effects of respite, when use may only tend to occur when high levels of distress are experienced by carers (Hoare et al, 2002) Interestingly, Kersten et al (2001) found that carers of adults with severe disabilities who reported needs for short breaks had significantly poorer levels of mental health and vitality than carers not reporting this.

Recent work has emphasised the need for a better understanding of how *respite is perceived by those in receipt of it*. Strang and colleagues in reporting on the

Table 4: UK studies relating to respite effects

Author(s)	Aims	Design	Findings	Comments
Primrose & Primrose, 1992	To examine current practice in relation to 'geriatric respite care'	Audit of 125 consecutive admissions to hospital (including shared care, planned respite and crisis respite). Interviews with nursing staff and patients (if possible)	87 patients (some more than one admission) had a high physical/mental dependency. Mortality was v.low. The geriatric unit seen as, at times, meeting shortfalls in other services. 25% of carers reported difficulties caring for their relative post admission (most freq, bowel and mobility issues). Some lack of congruence bet. drs and carers views on improvement/ deterioration.	Approx 25% of patients had low MSQ scores
Homer & Gilleard, 1994	To determine effects of in patient respite on elderly patients.	GHQ administered to patients before and after respite.	No effect found on respite on GHQ, somatic complaints or QHQ anxiety and insomnia variables.	Includes some patients with dementia. In-patient respite 'one dose' only.
Stephenson et al 1995	To assess satisfaction of patients and carers.	Interview survey of patients (92) and carers sent postal questionnaires	High satisfaction with respite.	Interviewees attending three 'geriatric' day hospitals.
Hoare et al 1998	To investigate the relationship bet. the characteristics of the disabled child, and the psychological adjustment and current level of stress among carers, esp. re respite use.	Five quest'aires completed: The Development Behaviour Checklist, Gen. Health Quest'aire -28 (GHQ-28): The Robson Self Esteem Quest'aire. The Quest'aire on Resources & Stress (QRS-F) & the Coping Inventory for Stressful Situations CISS-Adult. Families interviewed.	68% of children unable to use oral speech and 84% some kind of incontinence. Respite users divided into 2 groups: current users and non users over previous years. Consistent association between carer distress (QHQ or QRS sub scales) and users were more optimistic about their caring ability	Authors see carer distress as a major factor influencing respite use.

Table 4 cont...

Author(s)	Aims	Design	Findings	Comments
Hanson et al 1999	Two main aims (1) literature review (see table 3) and (2) explore views of users re frail older people.	Three focus groups with 3 groups (carer, care worker and user representatives) covering education, information and support re respite.	Focus groups findings suggest that 'for family carers to realise fully the potential respite can offer they first require general education about respite. Nurses are unlikely to be able to provide support geared to individual preferences and situations'.	Focus groups were restricted to informational, educational and support needs of individuals needing to make decisions about the respite they may need to use or access.
Ashworth & Baker 2000	To determine what the carers said re benefits or otherwise of respite care to carers	Qualitative study including purposive sample to achieve diversity. 23 carers interviewed using semi-structured interviews. A selection of open ended questions about caring and respite care were asked.	A variety of respite used, in addition the costs of caring (physical exhaustion, stress) as well as positive feelings (satisfaction, closeness of relationship) commented on. Respite found to be a service that provided normality (detachment from real world means surviving, providing structure for the week) and freedom (this being commented on either respect to its presence or absence). Respite care perceived as service which enabled care recipient to continue at home longer than would otherwise have been possible. Home-sitting service most valued.	Study based on respite care organisations offering services in London.
Kersten et al, 2001	Examine the unmet needs of informal carers of disabled community and to compare their perspective people with disabilities and professionals.	61 face to face interviews with carers and disabled participants (using the Southampton Needs Assessment Questionnaire – carers version), and the SF-36 were administered). Telephone interviews with professionals.	Carers experienced similar health status to general population. Most frequently unmet need expressed for short breaks, domestic help and respite care. Carers reporting unmet need for short breaks had significantly poorer levels of mental health on the SF-36 than other carers.	Carers reported more unmet needs for short breaks whereas professionals reported more unmet needs for formal respite care.

Table 4 cont...

Author(s)	Aims	Design	Findings	Comments
Olsen & Maslin-Prothero 2001	To evaluate a nurse led, home-based respite service for families of children under five in order to establish parental experience, impact of service on their lives and the contribution to family well being.	Follow up evaluation with in depth interviews (with semi structured topic guides developed for all three interview stages) with parents of 18 families referred to the children's outreach service (one family dropped out of the evaluation).	15 families reported some or significant improvement in 'family well being'. Of five families describing 'significant' improvement from the programme, none attributed this to the respite itself. Respite reported that as being one amongst a number of elements which determined improvements in family and well being.	Study restricted to newly referred families.
Nicoll et al 2001	To investigate the interaction between perceived social support and carer satisfaction with respite.	140 carers of dementia patients who had accessed respite services were contacted and sent questionnaire. Medical Outcomes Social Support Survey; Carer Strain Scale; Geriatric Depression Scale. Three areas of satisfaction measured (satisfaction with respite care, perceived carer benefit from respite and perceived care recipient benefit from respite).	26 carers included in the analysis (18.6%). 17 (65%) has used residential respite. 17 (65%) day care respite, 4 (15%) house sitting service (there was overlap) Mean number in carer social support network was 4 (SD=3, range 0-12).1 Mean satisfaction scores showed respite benefiting carers (5.8, SD=1.9) more than patients (5.2, SD=2.2).	Satisfaction measured.

Table 5: Studies relating to respite provision for children published after McNally et al's 1999 review

Author(s)	Year	Country	Care Group	Focus
Abelson	1999	USA	Children with disabilities	Effects on carers of lack of availability of respite
Neufeld	2001	Canada	Children with chronic illness and disabilities	Perceptions of carers of different types of respite care.
Valkenier et al	2002	Canada	Children with medically fragile or complex conditions	Mothers' experiences of receiving in home nursing care.
Cowen	2002	USA	Children with developmental disabilities	Parental stress and respite care (discussion of child mistreatment). Programmes for at risk groups.
Beale & Reed	2002	UK	Children dependent on medical technology	Parental stress and technology dependent children.

experience of respite for caregivers for persons with advanced cancer distinguish between 'cognitive' and 'physical' respite breaks. They describe how caregivers identified respite as a mental state whereby they were free from the responsibility and worry about caregiving although this was 'rarely achieved'. Being physically separated from the caregiving environment was not seen as necessarily resulting in 'feelings of freedom' (Strang et al, 2002). Such research may help explain why reductions in distress/stress following respite may not be found by researchers and reinforce Donaghy's view that researchers need to ensure that their measures of effectiveness are appropriate (Donaghy, 1999).

Overview of review

- 1) Robust evidence on the effects of respite care is hard to find.
- 2) Problems with terminology, different types of respite services and extent of respite provided, makes it difficult to aggregate and compare studies.
- 3) Studies in the early 1990s focused on hospital respite, which in most areas of the UK has been discontinued. Some of these studies provide the strongest evidence on the effects on carers.
- 4) The overwhelming majority of research on effects focuses on short-term provision. No longitudinal study was discovered.
- 5) The main focus of research on respite relates to older people with dementia and children with complex learning needs. There is a paucity of research relating to people with physical disabilities (including Multiple Sclerosis) and mental health problems.
- 6) There is a lack of UK respite research regarding usage and effects for people from ethnic minorities.
- 7) A coherent, comprehensive body of UK research on respite care is lacking.

Interview study

Recruitment

Difficulties were encountered in recruiting participants to the study. Despite working closely with health and social care workers we received fewer enquiries regarding the study than anticipated. We were informed during the recruitment process that people did not volunteer because (a) they had not received any respite to date and perceived this was an inclusion criteria; (b) only a small amount of respite had been received (also a perceived disqualification) and (c) people were apprehensive to be interviewed lest it jeopardised the services they were receiving. A further significant factor was confusion regarding the term respite, especially as for some people, including staff, it was equated with residential care. We also encountered staff and carers who were of the opinion that (i) money should be spent on services rather than research and (ii) carers were 'over-researched'. In particular, carers did not distinguish between consultation exercises, audit, in-house satisfaction surveys and research. In addition, we discovered that some voluntary organisations do not necessarily have direct contact with individuals living in the community.

As the project progressed it became apparent that a limited number of health and social care professionals played a key role in recruiting participants. In fact 31 one of the 60 participants were recruited through six 'champions'.

A specific difficulty encountered was in recruiting pairs. We found that although one of the pair might agree, the other might subsequently decline. Carers, as well, after agreeing to participate indicated that the child or person they were caring for 'was not able to be interviewed'. This was particularly the case with children with complex needs and adults with learning disabilities. In some circumstances, although one of the pair had agreed to be interviewed and had been interviewed, the other was precluded due to illness or hospitalisation.

Interviews were undertaken between May 2001 and December 2002.

The study participants

Twenty men and 40 women were interviewed, of whom nine and 27 of the men and women respectively were carers. The age range of interviewees was 30 to 92 years (30 to 89 years for carers and 33 to 92 years for care recipients). Age distributions are shown in table 6.

Table 6: Age distribution of interviewees

Age (in years)	Carer	Cared for	Total
30-39	7	5	12
40-49	5	5	10
50-59	8	7	15
60-69	10	2	12
70 +	6	5	11
Total	36	24	60

Rates of participation varied across the care groups selected for the study (table 7).

Table 7: Recruitment by care group

Group	Carer	Cared for	Total
Frail elderly	11	9	20
Multiple Sclerosis	5	11	16
Mental health	2	1	3
Learning disabilities	10	3	13
Chdn. complex needs	8	-	8
Total	36	24	60

Of the 17 paired interviews, eight carers were caring for frail elderly people, five for people with multiple sclerosis and three for people with learning disabilities. In the one remaining case the care recipient had mental health problems. In the case of children with complex needs, no paired interviews took place.

Caring relationships

There was a wide variation in caring relationships and in all 20 different relationships were represented (table 8)

Table 8: Caring relationships* by gender and relationship

Hu cared for by wife	Mo caring for son	Partner caring for partner
Hu carer to wife	Mo caring for dau	Both carers /both with Disabilities
Fa carer to son	Mo cared for by dau	Friend help/care for friend
Fa carer for dau	Wfe carer to hu	
Fa cared for by dau	Wfe cared for by hu	
Son cared for by father	Dau cared for by mo	
	Dau cares for mo	
	Dau cares for fa	
	Sr caring for bro	
	Mo-in-law cared for by dau-in-law	
	Dau-in-law cares for mo-in-law	

* **Bold** indicates interviewee

Several interviewees described caring for more than one person, as illustrated in the quotations below:

'...but for the last 16 weeks we have had my mother-in-law staying here (as a consequence) we were getting some support, community nurse, community care services to blether to her once a week, make a meal, getting her showered and so on. We now have a social worker .. so R (my son) got an extra week at .. the village.'

Carer KK

'My dad has had two strokes so he requires physical help more than anything else ... mum requires more attention, through her mental health ... looking after her is far more difficult than looking after dad. Dad requires physical help, she requires more company, I suppose.'

Carer OO

Some carers also highlighted how caring responsibilities had to be combined with parenting responsibilities for dependent children. For instance one carer said:

'Everyday is Cornerstone. To give a bit of background, we have three little girls. It is our eldest child and she is the one with special needs and she's nine. We have another little girl who is almost seven and one who is four. So I have help every morning between eight and 10, so that they can see to J and I can get the other two off to nursery and school. So Monday to Friday from eight until 10 and then again Monday to Friday from three until six, which is what I always call my "manic time".'

Carer I

Another commented: 'As soon as my son gets heavier I'm going to need respite. Also I would like to have more time to spend with my daughter.'

Carer H

Carers also spoke of conflicting loyalties; 'guilt at abandoning' a loved one and how the use of respite might preserve a relationship

'..... I told my son he was going in. He gave me a hell of a fortnight before he went, but I stuck to my guns, otherwise my husband would have gone off and left me! They were very accommodating and actually managed to get one of their other clients to move a week. And my son liked it there. He enjoyed it.'

Carer T

'I remember when, just last year, when we were going on holiday, and I was really worried and I thought I might have to get her into two weeks respite and two weeks with the normal care, and Day Care said "do you want day care while you are away?" and I said that would be wonderful because I find leading up to going on holiday I upset myself. I don't want to leave her and I have to practically been told, well you have got to think of your husband. But I don't want to leave her. I feel guilty, It is a terrible thing.'

Carer EE

'... but we also wanted it for the selfish reasons that, well, if we could get M settled, we will have many years to ourselves where we can do the things that we want to do without first having to make arrangements for M to be cared for. But, unfortunately, I'm not going to get that now because before we got it (my husband) died.'

Carer FF

'... I go out and tell everybody about it (respite). Tell everyone my experience of it and say that my husband and I would not have had any time together at all, if it hadn't been for respite'

Carer EE

'... we have a caravan, or my husband and I go away to a hotel maybe for a couple of nights every time ... just go away or just go out for meals and things'

we can't do when H is at home. Just to go to the pictures. Sometimes just have a long lie, or as H is on such a strange diet it's sometimes nice to have a carry out ... Just things that I would say that other people take for granted, we do try to, when she's in respite, do for ourselves.'

Carer MM

'... for the first time we understand what respite is, my wife needs a break from her mother rather than from R. We have never seen it as necessary to get respite for him but we go on along with it for training for his future..... He will be quite happy there and we are happy that he goes there, because all the time he's away it is like in preparation for the day when he will be left on his own. So the word respite for us, uhmm we don't have an awful lot of problems with him, that we need 'respite' for, but we would take as much time as we can to improve his ability to be somewhere without us'.

Carer KK

'... There would be more time for me to be able to spend with my daughter who is 12. It is difficult for her to go into town with us as she gets embarrassed by her brother.

Carer H

'... In my situation having an older boy and a younger boy and the younger boy's got special needs you never have time for the other one you know and it's very hard.'

Carer O

'It was really strenuous you know, because as soon as you leave him and he cried and you cry and you think "Oh no, I can't do this any more".'

Carer OO

Participants health and social support

Health

Interviewees' health is considered here firstly in terms of their scores on the Nottingham Health Profile (NHP), the Hospital and Depression Scale (HADS) and subsequently from accounts provided during interviews.

Nottingham Health Profile: Fifty three of the interviewees completed the NHP, including 19 of the 24 'cared for' and 34 of the 36 carers. Overall, carers' scores were lower than those cared for, although across both groups there was a wide range, as shown in tables 4a and 4b. Carers' scores indicate that they had a similar health status to that of the general population.

Hospital Anxiety and Depression Scale: Fifty three interviewees completed the HADS. Scores on the depression subscale were similar to a general population but on the anxiety subscale eight people had scores indicative of moderate to severe levels of anxiety. (tables 5a & 5b).

In carers own accounts of their health problems, many said how their health had been affected by their caring responsibilities. Commonly carers made reference to the stresses of caring.

'I have help every morning showering her, because I have osteoarthritis. So it's becoming difficultsometimes it's nice to have an unbroken night's sleep. I would like more of a respite ... definitely.'

Carer MM

'..... he only sleeps for three/four hours a night it makes me knackered, really tired.'

Carer O

Table 9a: Carers' scores on The Nottingham Health Profile

Cared for Group	Score (median)	Range	Nos Completed
Frail Older	12	0-25	11/11
Multiple Sclerosis	7	3-11	4/5
Child Complex Needs	2	0-12	7/8
Adults L. Disabilities	3	0-13	10/10
Mental Health	2.5	2-3	2/2

Table 9b: 'Cared for' scores on The Nottingham Health Profile

Cared for Group	Score (median)	Range	Nos Completed
Frail Older	9	4-15	8/9
Multiple Sclerosis	14	2-22	10/11
Child Complex Needs	-	-	-
Adults L. Disabilities	-	-	0/3
Mental Health	18	N/A	1/1

Table 10a: Hospital Anxiety and Depression Scale: Depression Subscale

	Older People		Multiple Sclerosis		Child Complex Needs		Ad. Learn. Dis		Mental Health	
	Carer n=11	Cared for n=8	Carer n=4	Cared for n=9	Carer n=8	Cared for -	Carer n=10	Cared for -	Carer n=2	Cared for n=1
Normal	5	5	3	6	6	-	6	-	2	-
Mild	2	3	-	1	1	-	2	-	-	-
Moderate	1	-	1	1	1	-	2	-	-	1
Severe	3	-	-	1	-	-	-	-	-	-

Table 10b: Hospital Anxiety and Depression Scale: Anxiety Subscale

	Older People		Multiple Sclerosis		Child Complex Needs		Ad. Learn. Dis		Mental Health	
	Carer n=11	Cared for n=8	Carer n=4	Cared for n=9	Carer n=8	Cared for -	Carer n=10	Cared for -	Carer n=2	Cared for N=1
Normal	9	7	3	7	7	0	10	0	2	0
Mild	1	1	0	2	0	0	0	0	0	0
Moderate	0	0	1	0	1	0	0	0	0	1
Severe	1	0	0	1	0	0	0	0	0	0

'I'm getting older and I am not so able now, and I would like more respite if it is possible..... They said that I should be getting more help and I have got osteoporosis as well ... so I am nae very healthy myself.'

Carer B

'.. our new GP was wonderful. He realised the problems and the difficulties I had healthwise. I had been diagnosed with this and it was very debilitating and the time before the medication, before they could just get the right medication, there were a lot of tests and one thing and another, biopsies and different things done, and of course, with having a new doctor and him starting afresh with all the history of my health and with the tests that were getting done and what was wrong with me. And he said one time I was down, he said "you know, you are exhausted, you are tired, you have a family but you think your main thing is to look after you mum."

Carer EE

'... but as you get older your respite needs change, totally change. You're not needing out for social activities, or L's social activities. It's physical, healthwise, every way you need the respite. It changes over the years.'

Carer FF

'Yes, I had a kidney removed about six years ago. I had a terrible time with her then. I wasn't at all well and trying to cope with her. I look back now, I don't know how I survived.'

Carer QQ

'I think as well when you know that it is coming up you take a different attitude to it because a week ago I couldn't see a light at the end of the tunnel at all, and I thought how many more weeks can I do it for, and it just gets so exasperating.'

Carer PP

Now, that is what bothers me (if spouse were to become ill) because I really don't know what would happen. A couple in a similar situation the man took a stroke. Well, they took the lady away to the hospital at the same time, but I don't know if that would happen in V's care. I don't know what would happen to him if I was ill. That would really worry me and make it worse.'

Carer A

Carers of sons or daughters with learning disabilities were particularly concerned regarding the impact of disabling ill health or their death:

'We are getting older, my husband and I. Last Friday my husband had two small strokes which brought it home to us that we are not going to be around for ever and I think the more B gets used to not being with us will be beneficial for her.'

Carer DD

'Well because F is 34 and I am moving through my 60s now, my middle son, who is a doctor, feels that I should be moving to more long term care, you know to get it in place. We wouldn't expect it to happen this year or next year or over the next five years, but as long as we could see that there was something coming up before I got to 70 and there is a chance that you might die off in your 70s.'

Carer JJ

Several carers thought their health concerns, coupled with a perceived lack of services made for additional sources of stress.

Interviewees, as care recipients, saw their own health affected by worries they had regarding their carer's needs, as reflected in the following comments:

'I would be able to relax more. I wouldn't have to worry about all the pressure I am putting on my partner. Because that is what it is, that is what I do. I put a lot of pressure on him and he gets upset as well because he doesn't know what to do. We don't get much help because if we phone the CPNs, all he gets told is 'well he's your partner, you deal with it.' So it is not there (respite) to give him a break when he needs it either.'

Mr R

'..... the nearest thing (to respite) I had was spells in hospital [it] can't really be classed as respite because it didn't give D any respite because she kept coming up to visit me in hospital twice a day'

Mr CC

Often interviewees stressed how important it was for them to maintain their health as there were few other people to whom they could turn. Social support is, therefore, considered below.

Social support

Both scores on the Social Support Questionnaires and responses given at interview indicated that for many interviewees support networks were fragile and in most cases were small in number, comprising a limited number of individuals.

Social Support Questionnaire: Fifty interviewees completed the SSQ. A low level of social support was found across all five care groups. As might be expected carers had more people upon whom they could call than those who were cared for, as is shown in Table 6a. In many cases the number of people upon whom people could rely was substantially lower than the numbers would suggest as indicated in Table 6b.

During the interviews there was little reference to others providing support external to the caring dyad. Extended family members were seldom mentioned and friends were not commonly identified as providing either help or friendship

[describing] so it is that sort of service (emergency) that you need. I don't have family and I couldn't ask a friend'.

Carer JJ

'I cling to the support. I have [a CPN] because my family is too far away. All of them live in England.'

Carer T

Although rare for participants to describe regular help from family, in one case (Carer KK) considerable support was described, as follows:

Table 11a: A Social Support Questionnaire (SSQ): Total support network size (median and range)

	Aberdeen	Strathclyde	Lochaber
	Median (range) n = 25	Median (range) n = 19	Median (range) n = 6
Cared (n = 35)	6 (3-18)	7 (2-13)	7.5 (4-16)
Cared for (n = 15)	4 (2-11)	4 (3-8)	3.5 (3-4)

Table 11b: SSQ: Examples illustrating nature of social support

Participant	No in network	Usual source of support	Comments
Carer N	7	Husband, mother	These two were be the most common support
Carer O	3	Mother (occasionally)	Despite total network, indicating three sources of support in some questions (14 out of 27) there was no-one she felt she could turn to.
Carer U	18	Wife	18 people are mentioned in this participant's network. Children, grandchildren, great-grandchildren and eight friends from the pub, feature infrequently wife is main support.
Carer FF	13	Children (4)	Her older children are the main support, but no-one mentioned for 4 questions
Carer OO	16	Twin sister, brother	Participant has a very large family network, but she lives in a remote area. Many relatives are far away including twin in U.S.A. who was mentioned often.
Mrs. E	4	Husband	Recently arrived and married in this country. Has email contact with U.S. but main person she would turn to is husband.
Mr E	10	Wife, sister	Despite 10 name overall, wife was the usual person.
Mr R	4	Partner	On most occasions partner/carer is usual support
Ms BB	7	Daughter	No carer. Despite total network indicating seven, in some question (11 out of 27) there was no-one mentioned.
Mr OO	4	Wife and daughter	Husband and wife live together with daughter who cares for them and hence she is the main support.

'You could say the other respite we have had is we have had the odd weekend where he has been passed on to another member of the family. That is, in fact, better than going away. So as long as he is with family he thoroughly enjoys this. So he is family orientated that way, very much so. So we, not very often, have him at other members of the family and we have absolutely no qualms about this.'

Carer KK

Further sources of support identified included support from voluntary organisations. Thirteen interviewees, in total, reported membership, and in some cases they were members of more than one organisation. Ten were members of carers associations or networks and nine, in total, reported membership of Crossroads or Shared Care Scotland. Three were members of the MS Society. However, organisations were seldom cited as a source of information on respite.

Knowledge of respite

Forty five percent and 16% of interviewees reported that they had 'a little' or 'no knowledge' of respite care, while 10% 'did not know' or express an opinion. Twenty eight per cent of respondents indicated 'a great deal of knowledge.'

Carers reported that they had learned about respite from a range of different sources. Information was most frequently reported as provided by social workers and general practitioners as shown in table 12.

Table 12: Source of information on respite services

Source	n=60 No*
Social worker/care manager	20
GP	9
Family & friends	9
Voluntary organisations	5
Other: School; clinic; district nurse	3

** does not sum, as some respondents mentioned more than one source*

Interviewees often had difficulties identifying respite care. 'Respite' was often seen as catch all term for a wide variety of activities. Clarification from the interviewer was often sought by care recipients, as reflected in the comments below:

'I didn't know that is what it is calledsomebody there [respite facility] said that was what they were there for – so I thought I must be here for it as well.'

Mrs BB

'Well the reason I couldn't say (in response to a question) is I don't know what respite is.'

Mr V

'Help around the house or something? I'm not entirely sure.'

Mr X

'Well I would feel that if I was having to do that (use respite) I would really be getting downhill. I really want to maintain what I can do on my own rather than going somewhere else. I have felt I have gradually been going downhill, but I would like to think that I can do as many things as I can myself, without depending on having to go somewhere else.'

Mr Y

'Well, it's just people who come and help me – isn't it really?'

Mr W

Carers less often sought clarification but many were unsure:

'I daresay that the Carers Centre does respite in people's homes – but they don't call it respite. I can't remember what they call it

Carer DD

'Well the family based (respite) is ... I mean I've got my own family now so they take her away to give me a break or they'll come to the house and stay with her to give me a break.'

Carer FF

From the interview data it was apparent that participants' knowledge tended to relate specifically to the services they had received. Commonly interviewees were not aware of the range of services which existed. Few of those interviewed appeared to know how to access services directly. One carer said *'I honestly don't know what I'd do'* (if emergency respite care was needed). Few interviewees made reference to carer support workers or use of carer centres.

Interviewees' accounts of accessing respite care often included reference to chance events, as illustrated in the following:

'I was pushing J in her buggy. I had the baby in the carry cot screaming and crying and the social worker happened to come up and say "How are things going?" and I just completely broke down and that's when it all started. She said "You really don't have to struggle" so that's when it all came into place. Until then I was just not aware of what there was and that there was help out there. Since then we have just never really looked back. It was all put into place very quickly.'

Carer I

In the course of describing what respite was, several interviewees raised queries regarding entitlement and issues about payment.

'.....I didn't know that payment for respite was limited to 28 days per year something I am picking up a wee bit [through the carers network] is that there is not an awful lot of it is laid out.'

Carer KK

'Well the care aspect can be taken from my wife and put onto someone else, but with her working full-time it seems that we get charged for everything. So in other words you can buy in respite but it is not available readily put in that way.'

Carer V

'.... but what I'm finding out with respite is you can have one sort of respite but you're not allowed to have the other sort of respite and in my situation I know I don't know.'

Carer O

'Well, everybody says that type of care [residential respite in a nursing home] will be worked out for you. Then we get this bill through the post after all this time ... they said it was free but it actually turns out that the council pays so much as we pay something.'

Carer U

Some uncertainty also emerged as to whether holidays arranged for a cared for person could be classified as respite. On the other hand family holidays were not necessarily seen as respite for the carer.

'So if I could have somebody to help then we could actually all have a holiday, but I am already beginning to dread it, and I try not to because I think it should be a family time. But I know what lies ahead and it is hard work, I think because I am so used to having so much help at home.....'

Carer I

Carers often described their main source of respite as being services their partner/relative received

'Well, day care I would say that is respite for me. I would say as the carer it is respite for me. Also the community carer that mum gets, again is respite for me.'

Carer EE

'Well, it's respite in that it means that I don't have to put J to bed. They come in every night and do it for me, a service for her. They bath her and give her supper and put her to bed, so it's respite for me.'

Carer FF

A small number of carers, however, made a clear distinction between services set-up for a cared for person and personal respite for themselves:

'Well actually, I don't actually (see it as respite) because I don't see the personal assistant and I don't see R's day centre as respite. I see it as a bonus.'

Mr Z

Use of respite

Forty eight of the interviewees reported that they had used respite in the previous 12 months. The main type of respite used was residential care (Table 6). This included residential, nursing and holiday homes.

Table 6: Types of respite used

n=48*	
Types of respite	No
Residential care	18
Respite in own home	13
Hospital respite	12
Emergency respite	5
Family based respite	3

* more than one type indicated

Dissatisfaction with the type of respite available had led six participants to decline it.

'What I was offered by the social services I would not have let my husband go out to(he) requires motivation. In nursing homes people are left to sit. There's no motivation whatsoever.'

Carer AA

'I mean [service provider] were doing three day breaks, but that wasn't very successful because when I enquired - I have two dogs and a cat - I mean I could take the dogs with me, but the lady wasn't awful sure if they would feed the cat. I mean she said if there was food they would feed it. But I thought "no". So I said well obviously she would cook for my mother, and she replied with "as long as there is stuff in the cupboards". So I didn't go any further with them'

Carer AA

'They referred nursing homes to me and they said there is a nursing home here, but that's not what F needed. She doesn't need a nursing home. She needs somewhere where she can go and enjoy herself. I always think it's got to be dual purpose before respite works.'

Carer MM

'... there was a place in Cove, a big castle, and my daughter went there once and it was like, oh my god, it was like Dracula's house! The gates were locked and the children were of very high dependency that were there. I just felt that I didn't want my daughter to be in that sort of set up and I wouldn't let her go back again.'

Carer DD

'No, and we would never, ever ever use [hospital wards or nursing homes] That to me is not what respite is.'

Carer MM

'When I put B into respite, a number of things happened. Last three times she has been put into respite, in hospital, and every time she comes out two things happen. One, she comes out with a sore on her body, sometimes more than one, which takes about six months to sort. Number two, she is twice as bad as when she went in, maybe even three times as bad. So it takes us about another three or four months to get her back down to the normal state before she went in. So it is a damn sight easier for me to keep her at home twelve months of the year than putting her into respite.'

Carer F

In many interviews carers expressed the view that caring for a husband or child was an integral aspect of the relationship therefore, they did not anticipate or expect the provision of respite. One carer considered that older carers were less likely than younger ones to seek services:

'... Certainly most people I know don't know about respite care because I would think (that is true of) people of my generation, especially if we are left with an old mother or we are left with a handicapped or damaged child. That is accepted by us that this is the way families are, that is the way things are. It is only a few who are aware instantly that there are agencies and help available somewhere else. Even then, when you are aware of that, you still have this overriding principle that it is our job to get on with it.'

Carer KK

Experiences of some kind of respite provision in the past also affected some carers' decisions regarding usage and most frequent reference was to residential respite, especially in hospital wards.

In addition some carers reported that their child or spouse's dissatisfaction with respite had led to them discounting it.

The role of respite: It was evident from interviewees' comments that respite performed a range of functions. The main ones were: to give time to spend with other family members/friends; to help the cared for person prepare for when the carer would no longer be alive; to help the carer when they are tired or ill; and enable the carer to cope in a crisis. Examples are given below:

' you go in for a week and they look after you and cook your meals and it gives your partner a break. He finds it a big help because he is bad with depression as well, so he needs some rest too. He says it is just fine coming home and relaxing to an empty house, he hasn't got to worry about me.'

Mr.R

'... the way we work is that I have family support (respite). So it is really basically to help the family. But what I find helps most is if I concentrate on the two little ones every morning and they (care workers) comes in and do everything for my young daughter who is profoundly handicapped'..... 'My husband's mother died quite suddenly last year and that was down in Glasgow. We were able to have emergency respite through (named service). They were super. It was super not to have to worry about (our young daughter).'

Carer I

'I think what she's got next week is classed as emergency respite because I was so upset and I was really scared that I would do her damage. I had to stop myself because I would have and I am scared if I was, I wouldn't know when to stop I don't want to do that and I don't want her to feel that she's not wanted because I do love her and I do want her, but I just want a wee bit of life to myself and its very difficult.

Carer N

Interviewees who had been carers for many years highlighted how their needs had changed over the years:

'So the respite element has taken over more of a kind of 'respite role' compared to that our original intention was which was the independent thing. But I think the way things are moving just now, and as we become less able to deal with B, as we would want is also due to physical reasons. I mean there used to be a day when she was smaller, she would dump herself on the floor and I would lift her up. I couldn't attempt to do that now.'

Carer GG

'I never had respite for F up until my husband died, which was 15 years ago, and F was only 20 and I still had family at home, so we didn't have respite as that wasn't a problem. I have got four children in all, so there was usually somebody around. But after my husband died, then two of my boys have left the house then so it was just J. I and F. Then I applied for respite and just started to get it from then, but I can't remember how I set about it.'

Carer JJ

In one interview a carer in discussing how needs had changed presented an alternative view of respite. As a parent of a son with learning disabilities she said:

'I would just like him settled in a nice place and then he can come back to us for respite [then] he will have his home, his other home to go to.'

Carer JJ

Overview

Four major roles for respite were revealed across care groups during the interviews. These we identified as follows:

1. **'Important for when I won't be here any more.'** This was particularly strongly articulated by carers of people with learning disabilities.
2. **Enabling a crisis to be overcome.** In many cases this primarily related to external events affecting the carer, such as a bereavement. However, reference was also made to highlighted caring needs because of a deterioration of the health of the cared for person and the carer's inability to manage the situation.
3. **Helping to overcome physical and/or emotional exhaustion, ill health enabling a carer in poor health to continue caring.** This was commonly expressed across all care groups.
4. **Providing time to spend with spouse and/or family members.** This was most commonly reported by parents of children with complex needs.

In addition, as is evident from the above section, interviews highlighted confusion regarding *'what counts as respite and what doesn't'* and what was available. Finally the qualitative study revealed diversity in a number of respects including: caring relationships, respite provision and use and respite provision and home circumstances, especially regarding how these could change over time.

Case studies

In the next and final part of this section, five case studies are presented. They enable the elements previously discussed to be joined together, giving an holistic picture of the lives of interviewees. Significantly they offer the opportunity to learn more about the social context in which respite has been experienced. The first case study is based on an interview with a mother caring for her six year old son. This is followed by case studies constructed from four paired interviews. The latter enable the voices of both parties to be heard.

Ms Stephenson and Sam

Ms Stephenson cares for her son, Sam, aged six years, who has an older brother (Neil). Sam requires help with most things, for instance he cannot feed himself and requires to be in nappies, but is able to drink from a cup. In particular, Ms Stephenson, aged 35 years, finds it difficult to cope with Sam's sleeping patterns as he usually sleeps for only three or four hours a night and, when he wakes up, she has to *'talk to him or put on a video for him or things like that'*. Sam attends a special needs school and, each weekday, a bus comes to collect him to take him to school.

Sam has been going into respite for two years, but Ms Stephenson feels that with *'a lot of respite services you've got to wait an awful time to get there. What I've found is I need to push and push and push to get Sam into respite because, if he doesn't sleep, [then] my older boy doesn't sleep because they both share the same room together'*. Information about respite was obtained from a social worker who, she says *'was brilliant . . . she got me quite high up. Well, she sort of pushed to get me quite high up the list and then what she did was she said to me to write a letter to the respite services . . . so what I did . . . I wrote a letter explaining the situation, but I still had to wait two years to get in'*. However, in the past, Ms Stephenson has had problems trying to get information and says *'every time you write to somebody or you*

ask somebody [it's a case of] "oh yes, we'll do it for you, it's not a problem". But they never ever get back to you, so what you find is you've got to go on paddy's wagon and do it all on your own, you know, which is not right. Your social worker should tell you all these things you should know'.

Sam goes to a residential unit for respite every month. One month he goes in Monday to Friday and the next month he goes in Friday to Monday. At first, Ms Stephenson found it quite hard to leave her son as *'it was really strenuous, you know, because as soon as you leave him and he cries and you cry and you think, oh no, I can't do this any more. But now he goes into Careaway and what we find is the people that he goes in with goes there the same time as he does, so he knows the people so it is quite great and he's the youngest one in his group, you know . . . so it's great'*. She finds it reassuring now that *'he loves it, he loves going! You know, when you say "Sam, you're going to Careaway" and he'll say "yes please! Yes please. Go to the ball pool! Go to the ball pool!"'* Despite the fact that Ms Stephenson should have a break every month, she finds that it does not always work out like this. *'I had Careaway in July and then I had it again in October. So that was an emergency bed I got in October when I phoned up and I said "look, this is not on. This is three months I've had without a rest".'* She also told them that *'if somebody phones up and says "can I have this emergency bed?" that means Sam doesn't get in. So that's another month I've got to wait'*. In response, the service provider moved Sam *'off the allocated emergency bed'*.

Ms Stephenson mentions that her son has had to go to hospital for various operations, but considers that *'it's not a respite because you're back and forth to the hospital – like three or four times a day and it's not a respite . . . when he's in, I am in [hospital]'*.

One weekend a year, her elder son goes to a youth club outing and she tries to get her young one into Careaway at the same time as, in her words, *'that's my one weekend a year that I have no kids. No kids from Saturday to Monday lunchtime. I never hardly ever go out you know, but it's just for me. You know, instead of being a mum all the time, I've just got to be me'*.

During the school holidays, both her sons attended playgroups (at a small charge to herself) for a various number of days a week. However, when they get older they will no longer be eligible for the play schemes. Sam goes to clubs for disabled children on a Saturday, and a care worker takes him to these. Sam also attends a special branch of the Boys Brigade.

Two and a half years ago, when Ms Stephenson was invited to a wedding, she wrote to the social work department to enquire about respite. As a result, she went to this wedding. This was possible as Sam was put into residential care and was there from *'two o'clock so I could get to the wedding. At 4pm the following day I picked him up. But that was horrible . . . because I was so I know it's maybe a horrible thing to say, but there are some worse off children than Sam it was just not for him, but it was the only thing that I had, you know.'*

Ms Stephenson is aware of a home based respite service, whereby *'they take your child away you know, they take him from one afternoon to four afternoons and I applied for that. But I found out that I can't have Careaway – you can have Care – or you can have [the home based service] but you're not allowed the two of them. But that's very unfair, because some people have got [both] you know'.*

Ms Stephenson would like to make a greater use of respite services, particularly as she is *'trying to hold down a college course and trying to catch up with the house and do everything. You know, I find it very hard sometimes and sometimes, I must admit, I stand outside that back garden screaming and because my stress levels are too high, you know. You just go out screaming. Normally, when I come back in I'm okay, you know'.*

On future needs for respite, Ms Stephenson feels a bit unsure – *'we just don't know what the future brings, you know'.*

Mr and Mrs McCoy

Mrs McCoy cares for her husband. Mr McCoy has had multiple sclerosis for 25 years and has been looked after by his wife for the past 12 years since she gave up full-time employment. Mrs McCoy says of her husband *'he can't do anything for himself at all. So he needs to be washed, toileted, fed . . . everything you would do for yourself . . . from getting up in the morning.* Mr McCoy said *'There are times that you could do things, but the trouble is that I can't do things on my own. My wife or someone has got to be here to assist me in doing everything. It's very frustrating.'* Mr McCoy does, nevertheless, find it *'a big help'* that his wife does everything.

Mrs McCoy told us that there are district nurses who come in, but says *'that is not respite, that is something different.'* She described how the district nurses have *'only been in the last three years'*, saying that *'I did my back in three years ago and I had to shout for some more help. So [they] come in each morning and get my husband up and toileted and washed and what have you.'* Her husband is on medication and suffers from bladder and bowel problems.

In addition, two care workers from Freeway come into the home. They come in two afternoons a week for three or four hours. This allows Mrs McCoy to get out (to pay bills, to go bowling, to play tennis). Recently, the same service was extended to two evenings a week for an hour or so. As they have had *'the same girls'* for the last nine or ten years, Mrs McCoy feels this is *'superb, so there is a good relationship . . . you have got to feel comfortable with the person who is coming in. I mean sometimes they go on holiday or the other one can't manage it, then you get someone else and they are all very good'*. More recently, there is someone else who comes in on a Sunday and, using the special lifting equipment, they are able to give her husband a bath. Mr McCoy spoke of the *'people from Crossroads come in twice a week and they come in and give my wife a hand so I can have a bath and the girls that come in during the week stay and help'*.

Mrs McCoy considers she has a little knowledge about respite, but *'didn't used to use respite. We used home based respite in [the local organisation] for carers. So I know a lot about that. As for respite outwith the home, I really didn't know an awful lot until about two and a half years ago'*. At that time, she felt her health had started to suffer, so was encouraged to look into other forms of respite. However, in her view, *'What I was offered by social services, I would not have my husband going out to them . . . [my husband] requires motivation. In nursing homes, people are left to sit – there is no motivation whatsoever'*. They had been to see the place that was available through social services and, although she believed it would be suitable for some groups of people, she felt her husband would not be one of them. Mrs McCoy then learned about a place her husband would be able to go for respite as he was eligible because he had been in the armed forces. This, she learned of through a relative who worked in healthcare. The unit, which was residential, would cater for Mr McCoy's nursing needs. She and her husband went to view the place and Mrs McCoy said *'I was suitably impressed and, more than that, my husband felt comfortable with the surroundings, which was the main thing. There wasn't any point in me saying "that is where you are going into" if I knew when he came back home he was going to be terribly miserable, because that is just not right'*.

Mr McCoy now goes for a fortnight at a time to the unit and cites such things as having entertainment every day and a physiotherapy unit. As well, there is a hairdresser and it's possible to have a manicure. Mrs McCoy comments *'it is all there for the fortnight that he is there and he can avail himself of that'*. Mr McCoy mentioned that *'there is always something going on and you can join in if you want and there is no pressure for you to do things if you don't want to go. You are not pushed into things you don't want to be involved in'*. Mr McCoy feels that going to respite is *'a good rest for both of us. My wife gets a break and it helps us both'*. He also feels it is a *'break from the everyday roles, if you like. Up in the morning and everything like that'*. As the other people in the unit are all servicemen, Mr McCoy finds *'we all have something to talk about, so it is quite a relaxing fortnight'*. Currently, Mr and Mrs McCoy are allocated eight weeks for respite. To date they have not used

this amount, but Mrs McCoy now plans to as *'I am getting that wee bit older and I am tiring, whereas before I was just rushing about thinking I was superwoman.'*

In using respite, Mrs McCoy can do decorating, meet friends for a meal, and is able to go on holiday. Mrs McCoy said *'when you become a full-time carer, you don't have the time, because if you are going out, even if you get a carer in, you are looking at your watch thinking you have to be back, so you are always clock watching when [Mr McCoy] is somewhere and he is being looked after, I am not worried'*.

Mr and Mrs McCoy had an assessment of income and savings and believed that the financial cost can have *'an impact on people not using respite'*. She thinks she probably *'held back from using it because I had to give up full-time employment I will probably use it a bit more now than my pension has kicked in – not much, but at least it is a wee bit more'*.

Mrs McCoy is a member of a local carers group. However, she does not always manage to get to meetings *'because of circumstances'*, but keeps up to date by *'reading the minutes'*.

As they spend *'a lot of our time together'* Mrs McCoy said *'we get out and try and do things. We always have done. We try and make our life as normal as it possibly could be within the limitations that we have'*. Mr McCoy said they went out for a drive or to do the shopping and look after their granddaughter once a week, saying *'you have to have eyes in the back of your head and watch her'*.

In a crisis, Mrs McCoy said she would contact her family, *'but where do you go from there? I could phone [residential respite] but whether, in fact, there would be anything available at short notice, that is a question mark'*. She said it was an issue that has been spoken about on many occasions.

Over time, Mrs McCoy believes the in-home support [from a local organisation and district nursing], as well as out of home respite, could change, but believes *'you can't forecast that. You just take a day at a time and see how it goes from there'*. In turn, Mr McCoy describes how his condition is *'just about what it has been all along, but it affects me sometimes more than others, but normally I have got my wife watching what I am doing and not overdoing it. I can get by'*. He does acknowledge, nevertheless, that as *'we are both getting older, there must come a time when my wife possibly will reach a stage where we need to have more help. She won't be able to do it all herself'*.

Mrs and Miss Walker

Mrs Walker is aged 69 years and has been caring for her daughter, Heather, who has Down's Syndrome, for 36 years. Mrs Walker said her daughter can be *'unpredictable'* and cannot be left alone in the house as *'she may open the door and let people in or talk on the phone'*. She helps her daughter getting up in the morning, checks that she has a bath and ensures that she is dressed appropriately for the weather. She may also prepare sandwiches for a packed lunch. She says it is important *'just to be here – [for] someone to be in the house'*.

Heather described how every day she has to *'get up early to get out to college'*. *'First of all'* she said *'I have to get something to eat inside me, then after that get ready, get all my stuff done and out for college'*.

Heather goes to a day centre three weekdays, while the other two weekdays, she attends college courses. Heather discussed how she prefers to attend the college because *'you can do your course which I like to do. I like to do different things'*. She leaves for her day centre and college activities at 9 am and returns home after 4pm. For the last two years, Heather has been travelling independently to the day centre and college, using public transport. Heather pointed out that college *'isn't far away, it is just up the road'*. She continued by describing the variety of different courses she takes, including

literacy in English, the magazine group, cookery and mathematics. She said that her favourite subject is literacy in English because *'you learn to read and I want to start reading'*.

On one night every fortnight, Mrs Walker accompanies her daughter to a social club for people with learning disabilities. Mrs Walker did not regard this as respite for herself, as she was one of the main organisers and attends in this capacity. In addition, she described how every fortnight her daughter goes out with a volunteer befriender. They go on a variety of different outings, such as going to the cinema, sauna or playing badminton.

Initially, when Heather was aged 11 years, she had been to the only place available for respite at that time. However, as the children had very high levels of dependency and the building and its set up were not what she had liked, Mrs Walker did not send her daughter there again. Following this, Heather had gone to respite at an establishment for children whose parents had passed away, or were not able to look after them. Every six weeks, Heather went for the weekend. This unit had two respite beds, but as there were permanent residents, her daughter had, after a while, not been willing to go. Mrs Walker thought this may have been to do with it being *'other people's home, so the two people that went in there for respite were really interlopers'*.

Finally, about two and a half years ago, Heather started going to a unit reserved solely for respite for over eighteen year olds. The young staff, Mrs Walker feels, have *'ideas very different than from what the ideas were years ago. The idea here is more than, okay, the carers need a break, but the kids need a break from us because most have ageing parents and they can't be bothered going here – can't be bothered going there'*. Hence, she feels her daughter enjoys the activities like going for a meal, going shopping, visiting the cinema – that she gets involved in while at respite. Heather indicated that she would be going to respite the coming weekend and described how there would be a mixture of people from different day centres and said that *'we all mix in . . . and it is really good!'* She doesn't know who is going to be there before she goes, but says she likes *'to get to know who is on with me and get*

friendly with them, go out with them, have good company outside'. While at respite, she says they may go out and have 'a fish tea or something – it's nice'. Also, they may go to see the shops or get an ice-cream. One aspect she mentions is that they all 'pay their own way' if out for a meal and that 'this is really good!'

Mrs Walker believes that the four days one month and three days the next month is the full respite quota that her daughter can receive (this quota being set by the respite unit). Therefore she said she has not looked for any further information about respite. She believes this is the only place in her area available for respite for her daughter and thinks that they could do with another unit in the region that they live. Meanwhile, Heather mentioned how she looks forward to respite visits which occur at the end of the month and says it would be *'really good'* if she was to go more often and had even longer stays of two weeks, saying that *it would be okay for me!* When in the respite centre for longer, in the past, she found she enjoyed *'going out to places'* or *'going for a run in the bus'*.

Mrs Walker has never used respite provided in her own home. She said she *'hadn't even thought of it'* but adds *'if we wished to go to a dinner dance and there was respite for someone to come in for five hours, that would be absolutely great!'* In any case, she believes as they are getting older, the more Heather *'gets used to not being with us . . . will be beneficial to her'*. She described also how there is a *'sense of freedom'* for herself and husband when their daughter is not at home. Heather, in turn, said that sometimes her parents visit when she is at respite and she can phone them once to see how they are and they can phone her once to speak to her. She knows that *'they do something to enjoy themselves and we are away to enjoy ourselves'*.

However, when making plans for whatever she does, Mrs Walker will always be home for when her daughter gets back. She definitely considers that she stops doing things because of the need to be at home, but says *'you just live with it'*.

Mrs Walker described an emergency situation which had occurred a few months previously when her husband had had two strokes while at the family home. As it happened, she said, their daughter was at respite at the time, so a crisis did not occur. Fortunately, by the time Heather was back from respite, other family members were on hand to help both with her daughter and her husband. Mrs Walker acknowledges, however, that there is no emergency respite provided by her daughter's current respite unit, and that the situation would have presented a problem without their own family support network.

Mrs Walker thought that social work is *'your entry'* into accessing services. In her case though, they do not have a social worker and so her daughter has not been assessed *'for community care'*. Recently, she had completed application forms for her daughter to move to long stay care – something she would be working towards for the future. But she believed that there could be a wait of between seven and nine years from application *'to a space maybe coming available'*. Currently, she saw the respite used for her daughter at the moment as *'beneficial'* to *'get her accustomed to being away from the apron strings'*.

Graham and John

Graham has been cared for by his partner, John, for about eight years. Graham has been hearing voices for a number of years. The main things his partner helps him with are ensuring that he gets up, and that he takes his tablets. Graham says *'if I am really bad, I have got a habit of not taking my tablets. John has to encourage me to go and have a bath'*. Other difficulties Graham has to deal with day by day, he explains are *'when the voices are really bad, I get very agitated and I get upset and I start self harming myself, things like that. So that is my main problem'* [my partner has got] *'to calm me down and keep on top of everything. He does all the cooking and everything because of my voices'*. This is a situation that he finds is occurring *'near enough every day'* [but it] *'depends how bad the voice actually is. Some days I can be okay. I can manage to cook a meal, and the next day, when I am trying to cook a meal, everything just gets thrown about the kitchen'*.

All that Graham knows about respite he has learned from the service he uses twice a year. Graham explains *'you go in for a week and they look after you and cook your meals and it gives your partner a break. He is bad with depression as well. He needs some rest too. John says, on his return, it is just fine coming home and relaxing to an empty house. He hasn't got to worry about me, it is brilliant'*. Graham has been using this service for one year, the length of time he has known about the service after finding out about it from family and friends. In the first instance, he phoned up and managed to get a cancellation.

Graham has heard a little bit about a different type of respite in the community through a friend. He says *'it's like you can go to somebody's house. That is the only thing I have heard'*. He does not know whether each time you would return to the same house or not.

On each day of the week, except a Saturday, Graham attends a support service for his voice hearing. At this drop in centre, he takes part in various activities, including a voice hearing group comprising many different types of voice hearers. This offers opportunities to speak about any problems being experienced.

Regarding the respite he uses, he says *'it would be handy if you could have somewhere for when you are really bad and are really putting a lot of pressure on your partner. I would love to have a place where you could phone up and ask if you could fit me in for a couple of days. I would love a place like that, which is probably impossible to do if you think about it . . . it would be really good though, because sometimes, when you are really bad, you are putting a lot of pressure on your carer. I class it as a safe haven as well . . . I am also able to relax'*. Graham would definitely like more than the two weeks respite he is permitted each year. This is provided on the basis that *'they give you the dates. At the beginning of the year I was really bad, phoned up, phoned up and asked if they had any cancellations'*.

Graham finds that he and his partner do not get much support from his community psychiatric nurse, as when they phoned him, his partner was told *'well, he's your partner – you deal with it . . . so if I had more respite care it would give him more of a chance to get back onto his feet again, rather than going on for months suffering with me, and only getting a quick week. Okay, that week he does feel a difference, but then it is back to normal after the week'*. He says he would not mind trying another branch, based elsewhere, of the respite service he uses at the moment, as it would give him the opportunity to *'meet different people and give him a break [from his home town]'*.

Graham finds that he has too much time on his hands when he is at home. He can be *'really bored and fed up and annoyed with himself and that is when the voice starts to get really bad'*. Then he even likes *'just going out and walking around the town'*. Yet, he says, when he is at respite *'funnily enough I hardly go out'*. He is quite content to sit in there and watch television.

He says that he wishes *'there was someone he could speak to sometimes'*. That even helps you, he explains, *'to know if you are feeling really bad. Speaking to someone can actually make a big difference . . . maybe someone that you know that you can pick up the phone and have a speak to them . . . and see what they can advise'*. He has met up for coffee with people he has been to respite with, so the social aspects he enjoyed when at respite extended back into everyday life.

If a crisis was to occur, and John was to go away, then Graham thinks that *'one of my mates would come. A mate has stayed in the house with me. So it depends. Before I have stayed in the house on my own for three days when John was away, and I was okay'*. John believes, in an ideal world, having an extra four weeks of respite a year to go to every two months *'would make a big difference and, if it was flexible as well, that would be ideal'*.

Mrs Evans and Mrs Macdonald

Mrs Evans, who is 66 years, has cared for her mother, Mrs Macdonald (aged 92 years) for about three years. She says that she has to do *'everything'* for her mother, who has mobility problems and is confined to a wheelchair, as she has had a leg amputated. In Mrs Evans' own words *'I do it on my own and I do it every day, but on a Tuesday, just to give me a break from washing her and everything, I have a bath nurse that comes in'*. In the past, the service had been twice weekly, but this was withdrawn. Mrs Macdonald goes to the local community centre twice a week on a Tuesday and Thursday for her lunch, where she is also able to have a shower, using the specialised facilities available there. In addition to this, Mrs Macdonald attends a craft club, where she also received her lunch. (Mrs Macdonald is still able to feed and drink by herself.) On occasions, Mrs Macdonald will have a day in bed on a Sunday and comments *'there are some days that I want to stay in bed. If I have had a bad night . . . then I won't sleep'*. Mrs Macdonald is *'quite happy up here . . . I am very well looked after'*.

Mrs Evans considers herself well aware of what is available for respite in their home region. The GP had initially been their main source of information. As well, she found that the first social worker *'helped . . . quite a lot'*.

Mrs Macdonald had been for respite in a hospital ward in a community hospital before. But Mrs Evans said that they *'didn't talk to her and she didn't like that, as she is really gregarious. She likes somebody to talk to. Even though she is 92, she can carry a conversation with you no problem'*. Mrs Macdonald now goes for respite at a community hospital and says when she is there she is allowed *'to get on with what I want to do'*. One thing that she had access to when at respite was a wheelchair that had wheels for outdoors and she found that she was *'so happy that I was able to get about. I think that makes a difference'*. On the most part, she has found that *'they are a real nice set of girls'*. However, on one occasion she had to wait a long time for the commode and was told she would have to wait until after breakfast, causing her a lot of pain. In another instance, a nurse had said *'aren't you*

dressed yet?’ when she had been needing help prior to being able to get dressed and she felt like ‘a load of dirt and [they] shove you out of the road’.

Mrs Evans’ mother is entitled to about six or eight weeks of respite a year and goes for a respite break roughly every four months, but feels there are times she could do with a three or four day break as well. She has held off using respite at times so as to build up the amount. She calculates *‘I have budgeted about 10 weeks, but I think when we wanted that other week we went 15 weeks without a break and, you know we did that to accumulate the other week you see, and we would probably have to do the same again’*. She commented that you have to book respite breaks quite far in advance and contact their local doctor to arrange for her mother to go to respite.

Mrs Evans had not followed up respite from her mother’s last visit as she had not been well herself. *‘I didn’t know whether I was coming or going myself’*. However, her mother was going for her next respite break the following day. Mrs Evans described how, when her mother found out, she said *‘I am going on my holidays. Where am I going?’*. And her daughter told her *‘you are going to Loch Lomond’* and her GP, who happened to be there at the time, said *‘we are sending you to Loch Lomond to give [your daughter] a rest’*.

Mrs Evans does not use any respite in the home for her mother, as when they go out they can take her with them – perhaps for a meal. Her husband commented that *‘there was no need to use it’*.

Mrs Evans saw things as accumulating. For example, there had been a problem with an alarmed mattress that was malfunctioning and was *‘prone to going off three or four times a night’*. She said that it got to the stage *‘where I am laid awake waiting for it to go off’*. She added *‘When it happens, I go in and even though I could tell my mother was awake, I didn’t use to speak to her because I thought, if I start talking, it will be a cup of tea and then this and a chat and one thing or another. In fact, I have gone into the bedroom with my eyes closed sometimes because I know exactly how to cancel the thing I have been so tired. I have not lost my temper, but have been umm . . .’*

. . . I have found niggling little things I don't sound like me I sound real miserable'.

Mrs Evans also described how everyday tasks can now become a chore. *'I find it real hard to do things like baking and cooking. I have lost all interest in doing anything like that'.*

An important aspect of her life is knowing that a respite break is coming up. In her words *'when you know that it is coming up you take a different attitude to it because a week ago I couldn't see a light at the end of the tunnel at all, and I thought, how many more weeks can I do it for? It just gets so exasperating'.* Even so, she found there could be problems when her mother comes back from respite. Her mother was seen as demanding. Mrs Evans said *'I have to say to mother, look, I have got to see to you, I have got to do the cooking and the washing. The cooking – mind you [my husband] helps me a lot. I make it a point most days of taking the dogs out for an hour. If I didn't, I think I would blow my top!'*

DISCUSSION AND CONCLUSION

Research design

The study reported here demonstrates the complexity of undertaking research on respite care. The challenges to be overcome may go some way to explain why the grey literature, so often produced by those with little research training and financial support, yielded so little. However, we are not the first researchers in this area to discover both the time consuming nature of searching for unpublished material and the difficulty in acquisition. Acton and Kang in investigating interventions for caregivers of people with dementia report:

‘Two hundred and nineteen (e-mails, telephone calls and letters) were sent to and received from investigators involved in caregiver research in an effort to collect missing data from published studies and to enquire about unpublished studies. No unpublished data were located, thus this report contains published data only.’

Acton & Kang, 2001; 254

Moreover, although the largest volume of respite research concerns older people with dementia there have been no reviews specifically focusing on effects. As a member of the Cochrane Dementia and Cognitive Improvement Group, has concluded:

‘although there have been reviews of caregiver interventions in general, a systematic review of the literature and data specifically assessing the benefits and adverse effects of respite care on quality of life, or morbidity or mortality, for people with dementia, or secondarily, for their caregivers has not been published’.

Lee, 2000

Unfortunately, to date the problems of accessing respite research and interpreting it go widely unknown, especially by service providers.. A major

consideration is the very wide range of publications in which relevant research may be published, leading to further cohorts of researchers rediscovering for themselves the pitfalls of attempting to evaluate respite care. The literature we reviewed here well indicates that the methodological problems have been known for over two decades. For instance the problems of recruiting people have been reported both in the grey and published literature. These difficulties, which so fundamentally affect the reliability of the data, especially regarding the representativeness of research populations, are likely to increase in the future. This relates to several factors including that the general population is less diffident to researchers and within the UK patients, service users and carers are becoming increasingly aware of their rights, including not to participate in research.

This study suggests that in order to achieve high rates of participation partnership with a voluntary agency is not enough. Direct involvement of respite service users in research, including data collection and analysis may, therefore, be a strategy which should be pursued. Involving carers in the research process, however, may pose considerable problems not only as time is in short supply but also they may not place a high priority on research.

Although we had limited success in recruiting pairs of participants (carers and care recipients) we feel it is important that future studies seek to incorporate both viewpoints. We see the paired accounts presented here as contributing to a newly emerging body of work in this area, such as that by Kersten et al, 2002 in England and Coeling et al, 2003 in the USA. The latter, report a preliminary analysis of how caregivers and care recipients negotiate the informal care dyad's rules that influence how the care experience 'fits into their lives' and go on to suggest a theory based on their data (Coeling et al, 2003). Interesting to note is that the 2003 analysis is derived from a larger National Institute of Health funded qualitative study of 60 informal care dyads and their use of respite care (Biordi, 1993).

Caring relationships and outcome measures

A significant finding of our study was the very wide range of caring relationships found. We had as participants not only spouses, and daughters caring for parents, but also a mother-in-law caring for a daughter-in-law and a son cared for by his father (table 8). Although previous research has highlighted the 'quality of the relationship' as a key aspect of caring (Quereshi & Walker 1989) we know of no previous work where such a diversity of caring relationships has been reported.

Types of caring relationships, therefore, need to be taken into consideration in determining effects, but our literature review indicated that this key variable is seldom taken into account.

At the start of the study we sought to identify measures which might be employed in establishing the outcomes of respite care. Our analysis shows that although it was feasible for some carers and people within some care groups to complete them, for others they were inappropriate. We found also that the NHP and HADS, in general, were not sufficiently sensitive for our population. Application of these tools as well made us acutely aware of the extent to which they were 'time specific.' We speculate that the social interaction which the interview itself offered could have influenced scores. The challenging nature of caring, over weeks, months and years to which many interviewees referred also highlights the importance of timing to the assessment of outcome, and points to the need for long term studies.

In addition, greater clarity is required regarding what is measured as outcome. Our interviews revealed that maintaining carers health was but one of the roles of respite. Therefore outcome needs also to be measured in terms of effects regarding preparation for the future, coping with crises and enabling time to be spent with other family members. For us the interviews overall demonstrated the multidimensional nature of caring and the importance of people's *perception* of their circumstances. We recommend that Strang et al's work is taken into account by policymakers. In particular, attention needs to

be paid to the distinction between 'cognitive' and 'physical' respite breaks (Strang et al, 2002).

Although in contrast to the NHP and HADS, the SSQ posed some difficulties in administration, it demonstrated the importance of investigating support networks when considering respite care. Small numbers of people were found in the support networks of care recipients (supporting Nicoll et al's earlier finding). Where carers, moreover, did indicate larger numbers, considerable reliance tended to be placed on one or two key people. Yet opportunities for informal respite will be limited where networks are small and clearly service providers need to take this into account when assessing services required. Network size is likely to be important to both the carer and care recipient in influencing the opportunity for social contact and reduction of social isolation. Both of the above have been seen to be associated with risk of depression. In addition, feelings of self esteem may also be affected by abilities to sustain social contacts. We advocate that in future respite studies, the size and nature of support networks is taken into account where attempts are made to establish outcome since respite provided by family members may be a significant part of the 'respite package' and affect outcomes regarding psychosocial health. Future research is needed, therefore, to develop appropriate means of assessing social support.

Despite the problematic nature of much previous respite research, those with strategic planning responsibilities are seeking research to underpin service development. Thus, it is a cause for concern how research may be selected. In particular, we believe managers need to be cautious regarding research undertaken in the USA, since it is likely to relate to care services rather than respite care. Concomitantly UK research may not necessarily be appropriate, since a number of studies relate solely to hospital provided respite.

The above points to the importance of researchers working with service and policy developers. We see this as including critical review of research as well as the development of relevant research programmes. Clearly this calls for joint working. Next we consider our experience in this respect.

Partnership working

We see this as having been promoted in this project by:

- a feeling of joint ownership, relating to the fact the project proposal was developed together between Shared Care Scotland and the research team;
- regular meetings held to discuss progress and agree future plans;
- the dissemination of new research by the research team;
- joint presentations made at meetings and conferences.

The main challenges involved have been: the geographical distance between partners; differences in working practices between a small community based charity and a large university and on occasions over expectations of each other. These related to the recruitment of participants on the part of the researchers, and to *Shared Car Scotland's* desire to have tangible outcomes for the work – ideally specific outcome measures for use. Overall the project highlighted the need for researchers to clarify the nature of research and to explain how it differed from consultation exercises and evaluation. The very small number of academic theses revealed by our search indicates the low volume of research training taking place within universities. Yet, as this report demonstrates the issues are complex and the research is challenging requiring specialist skills.

A further issue was that carers and those they care for, may also have reservations about approaches adopted by researchers. For instance, at some networking meetings those present objected to the focus of this research being on 'pairs.' Others were dissatisfied that recruitment had been restricted to specific care groups and parts of Scotland. The fact people had been excluded was not seen to fit comfortably with notions of social inclusion. However, at the final feedback meetings considerable interest was shown in the issues raised.

Main implications & issues

Implications

1. The complexity of evaluating the effects of respite care need to be acknowledged. In order to assess outcome as a minimal requirement detailed information should be provided on age, gender, health (nature and extent of any problems), caring relationship(s), social and health services received, type of respite services and sources of family support.
2. Respite research evidence to date is not robust enough to justify respite services. Given the complexity of measuring outcome, simple outcome measures are not up to the job, not least because of:
 - a) the diversity found in individual caring relationships and situations;
 - b) problems of identifying respite care (exacerbated by the range of terminology applied);
 - c) the changing circumstances regarding need, relating to changes in health status and family relationships, affected for instance by illness, death and marital breakdown;
 - d) the problems of isolating the impact of respite care from other service provision and family support.
3. Reliable systems of data collection need to be set-up to capture data relating to needs and respite provision. Various points of collection, such as hospitals, nursing homes and social work departments are needed.
4. Carers' information strategies, which are developed in response to the Community Care and Health (Scotland) Act, 2002 should address carers' needs relating to respite care. As well, respite care strategies developed by local authorities need to include within them information strategies. This has been the case for instance, in the strategy developed for Aberdeen City Council in 2002 (Mitchell & Chesson, 2002). We endorse the conclusions of Hanson et al that:

‘for family carers to realise fully the potential that respite can offer, they first require access to general education about respite. If family carers do not know what respite is or understand the variety of forms that it can take, they are less likely to be able to cope with information about specific services or know how to make effective use of the information. Likewise, nurses are unlikely to be able to provide support geared to individual preferences and situations.’

Hanson et al, 1999; 1403

5. Low expectations of respite care, both in terms of quantity and quality, may not be helpful to ensuring high quality respite provision. Study participants relied heavily on their own resources to make arrangements when necessary, even though there might be few family members on whom they could call upon to help. The value of self-sufficiency may place even more demands on families who are struggling to care for a family member. It is worth noting that Direct Payments, although not mentioned by our study participants also require considerable personal resources on the part of applicants to ‘manage’ the process.

6. Anxieties carers have regarding their own health, highlight the need for increased awareness of the risks associated with caring. Carers’ health issues therefore need to be considered as part of Public Health/Health Improvement Strategies. Closer working between the NHS, local authorities and voluntary agencies is required in order that both the health and social needs of carer and cared for are addressed. However, wherever possible they should not be regarded as separate entities.

Issues

The project identified that there is a need to:

- develop a realistic research agenda regarding respite.
- persuade policy makers that attempts to demonstrate effectiveness are premature (encourage caution regarding the evidence-based agenda).
- reconcile the individual's right to privacy and the right to decline to participate in research with the need for research.
- distinguish between people's needs and response strategies (some needs may be met by other means rather than respite services).
- distinguish core respite services from respite provided as a by-product of other services (especially important in the context of service funding) as well as to ensure clarity in terminology.
- develop strategies which facilitate *individuals* living in the community to access resources, facilities and services.
- acknowledge every scenario may be different and change over time. Olsen & Maslin-Prothero (2001) have previously drawn attention to changing need in the context of children with complex health care needs, highlighting that need is not solely related to the child:

'Changes in the support of families, however, were not linked solely to the unpredictability of the child's health care needs. Parents talked about their need for respite support in response to other life events ...'

However, it must be acknowledged that this is challenging for service providers.

Conclusion

We doubt that it is possible to propose a single measure or even basket of measures to demonstrate the effectiveness of respite care. In particular, our interviews indicated that an holistic approach is required, yet researchers are unlikely to be able to achieve this. Evaluating the total respite package, including both an array of community services and informal support is itself a major challenge.

Although we regard earlier attempts to measure the effects of respite by reference to carer stress as flawed, this should not be taken to suggest that we regard health as unimportant. Rather we think that the health of the care recipient and carer (and how this is sustained through care strategies) should be investigated *in its own right*. Indeed, following our review of the literature we recommend that, in particular, carers' health should be high on Scotland's Health Improvement Agenda. Concomitantly, it is timely to review the effects of the withdrawal of hospital respite since for so many years (and for so many people) this was the main source of respite care. Our research study would suggest that for many an alternative has not materialised and that health care functions previously performed by hospitals have not been taken on by community services. The current trend towards the categorisation of respite as solely social care is not only erroneous but may be deleterious.

This study has led us also to ponder if work to date to justify respite is misplaced. In the 21st century we live at a time when workers' rights to paid holidays are enshrined in employment legislation even though their effectiveness has not been established. Given that carers in Scotland are designated by the Community Care and Health (Scotland) Act, 2002, as 'partners in care' alongside statutory providers, it is time to consider the transferability of employment law to them. It may be appropriate as well to include respite as an entitlement within a developing charter for rights of people with disabilities.

Ultimately we feel the issues raised by this investigation extend beyond the scope of health and social care lying within the domains of human rights and morality. Fundamentally, respite provision is about how we as a society treat those who are disadvantaged through disability or by being a carer.

References

Abelson AG (1999). Economic consequences and lack of respite care. *Psychological Reports*. 85 ;3 :880-2

Acton GJ, Kang J (2001). Interventions to reduce the burden of caregiving for an adult with dementia: a meta-analysis. *Research in Nursing & Health* 24:349-604.

Ashworth M and Baker A H (2000) 'Time and Space': carers' views about respite care. *Health and Social Care in the Community* 8:1; 50-56

Beale H (2002) Respite care for technology- dependent children and their families. *Paediatric Nursing* 14:7; 18-19

Biordi D (1993) *In-home care and respite care as self care* (NIH Grant No 1 RO1 NRO35-32:01) Kent, OH

Brown J B, McWilliam C, Wetmore S, Keast D & Schmidt G (2000) Is respite care available for chronically ill seniors? *Canadian Family Physician* 46; 1793-1800

Callaghan P & Colquhoun S (1994) *Respite care for people with major mental health problems*. Report to Social Work Services, Central Regional Council

Chesson RA (2002) *Bon Accord: A review of the MS Society Holiday Homes in Scotland*. (Report to the MS Society)

Chesson R (2001). *Respite: Definitions and Policy*. Aberdeen: The Robert Gordon University. (Report to MS Society).

Coeling HV, Biordi DL, Theis SL (2003) Negotiating dyadic identity between caregivers and care receivers. *Journal of Nursing Scholarship*. 35 1:21-5

Cowen PS and Reed DA (2001) Effects of respite care for children with developmental disabilities: Evaluation of an intervention for at risk families. *Public Health Nursing* 19:4; 272-283

Cox C (1997). Findings from a statewide program of respite care: A Comparison of service users, stoppers, and nonusers. *Gerontologist*. 37: 4; 511-17

Department of Health (1995) *Carers Recognition and Services Act 1995*. London: HMSO

Department of Health (1990). *National Health Service and Community Care Act* London; HMSO.

- Donaghy M. (1999) Useful services for families: Research findings and direction. *International Journal of Geriatric Psychiatry* 14; 165-181
- Gottlieb BG & Johnson J (1995) *Impact of Day Care Programme on Family Caregivers of Persons with Dementia*. Gerontology Research Centre, University of Guelph, Guelph, Ontario.
- Griffin I (1994). 'Give me a Break': the need for Respite Care Report to Shared Care Scotland.
- Hanson EJ, Tetley J & Clarke A (1999). Respite care for frail older people and their family carers: concept analysis and user focus group findings of a pan-European nursing research project. *Journal of Advanced Nursing* 30 6: 1396-1407
- Hoare P, Harris M, Jackson P & Kerley S (1998). A community survey of children with severe intellectual disability and their families: psychological adjustment, carer distress and the effect of respite care *Journal of Intellectual Disability Research* 42: 3; 218-227.
- Homer AC & Gilleard CJ (1994). The effect of inpatient respite care on elderly patients and their carers. *Age & Ageing*. 23 4:274-6
- Horsburgh M, Trenholme A, Huckle T (2002). Paediatric respite care: a literature review from New Zealand. *Palliative medicine*. 16: 2;99-105
- Ingleton C, Payne S, Nolan M & Carey I (2003). Respite in palliative care: a review and discussion of the literature. *Palliative Medicine*. 17 7:567-75.
- Kersten P, McLellan L, Georges S, Miller MA, Smith JA (2001). Needs of carers of severely disabled people: are they identified and met adequately? *Health and Social Care in the Community* 9 4:235-43
- Kitching K (1992) *The use of respite services in north Staffordshire by families with a member with a mental handicap*. Unpublished MA Thesis, Keele University
- Koloski K & Montgomery RJV (1995). The impact of respite use on nursing home placement. *Gerontologist*. 35: 1;7-74.
- Lane P (2002) *An exploration of the health and social care needs and experiences of family carers of older people*. Unpublished PhD Thesis, Ulster University.
- Lawton MP, Brody EM & Saperstein AR (1989). A controlled study of respite service for caregivers of Alzheimer's patients. *Gerontologist* 29:8-16.

Lindsay M, Kohls M, Collins J (1993) *The Patchwork Quilt: A study of respite care services in Scotland*. A Report to the Social Work Services Inspectorate for Scotland, Edinburgh: Scottish Office.

Lord J (2002). *Information and guidance. Thinking about adoption or fostering? For those considering adopting or fostering a child*. London: BAAF Adoption and Fostering.

Lothian Short Breaks and Breaks from Caring Group (2000) *Breaking new ground: Rethinking respite provision in Edinburgh*. Edinburgh: Edinburgh City Council

Malonebeach EE Royer M & Jenkins CC (1999) Is cognitive impairment a guide to use of video respite: Lessons from a special care unit? *Journal of Gerontological Nursing* 17-21

Maynard LC (2000) *An exploratory study of the needs of children with life-threatening illnesses and their families and the potential role of the community children's nursing*. Unpublished PhD Thesis, Kings College, London University.

McNally S, Ben-Shlomo Y & Newman S (1999). The effects of respite care on informal carers' well-being: A systematic review. *Disability and Rehabilitation* 21:1;-14.

Miles MB and Huberman AM (1994) *Qualitative data analysis*, California: Sage.

Miller S (2002) Respite care for children who have complex healthcare needs. *Paediatric Nursing* 14; 5 33-37.

Mitchell L & Chesson RA (2002) *Developing a respite strategy: A resource pack*, Aberdeen: The Robert Gordon University. (Report to Aberdeen City Council).

NHS Centre for Reviews & Dissemination (1996). *Undertaking systematic reviews of research on effectiveness: CRD guidelines for those carrying out or commissioning reviews*. York: NHS Centre for Reviews & Dissemination, University of York; (CRD Report 4).

Neufeld SM, Query B, Drummond JF (2001) Respite care users who have children with chronic conditions: are they getting a break ?. *Journal of Paediatric Nursing*. 16: 4;234-44.

Nicoll M, Ashworth M, McNally L & Newman S (2002). Satisfaction with respite care: a pilot study. *Health and Social Care Community* 10 6:479-84

- Nolan MR (1991) *Timeshare beds: a pluralistic evaluation of rota based systems in continuing care hospitals*. Unpublished PhD Thesis, Bangor, University of Wales.
- Pomeroy VM, Warren CM, Honeycombe C, Briggs RS, Wilkinson DG, Pickering RM, Steiner A (1999). Mobility and dementia: is physiotherapy treatment during respite care effective ? *International Journal of Geriatric Psychiatry*. 14 5: 389-9
- Primrose CS & Primrose WR (1992). Geriatric respite care- present practice and the potential for improvement. *Health Bulletin* 50 5: 399-406
- Olsen R & Maslin-Prothero P. (2001) Dilemmas in the provision of own-home respite support for parents of young children with complex health care needs. Evidence from an evaluation *Journal of Advanced Nursing* 34:5; 603-610.
- Quereshi H & Walker A (1989) *The Caring Relationship: Elderly People and Their Families*. Basingstoke: Macmillan.
- Robinson C (2003). *Short Breaks in the South West of England for Disabled Children and Adults with Learning Disabilities*. South Gloucestershire: South West Learning Disability Network.
- Robinson C & Stalker K (1989). *Time for a break (Respite care). A study of providers, consumers and patterns of use and following reports*. London. Department of Health.
- Sarason IG, Levine HM, Basham RB, et al (1983) *Assessing social support: the Social Support Questionnaire*. *Journal of Pers. Social Psychology*; 44: 127-139.
- Sarason IG, Sarason BR, Potter EH, et al (1985) *Life events, social support and illness*. *Psychosomatic Medicine* 47;156-163.
- Scottish Executive Health Department (1999) *Caring about carers: Strategy for carers in Scotland*. Edinburgh: Scottish Executive.
- Scottish Office Social Work Services Group (1996). *Community care in Scotland: Guidance on respite care*. Edinburgh: Scottish Office. Circular No: SWSG 10/96.
- Scottish Parliament (2002). *Community Care and Health (Scotland) Act 2002*. Edinburgh: The Stationery Office.
- Smith MP (1988) *Caring for carers: an evaluation of a domiciliary respite care scheme*, Unpublished MA Thesis, Durham University.
- Stajduhar K, Lindsey E and McGuinness L (2002). A qualitative evaluation of an HIV/AIDS respite care service in Victoria Canada. *Evaluation and the Health Professions* 25 3: 321-344

Stalker K (1987) *An evaluation of a family-based respite care scheme for children with mental handicap*. Unpublished PhD Thesis, Edinburgh University

Stephenson C, Wilson S, Gladman JRF (1995) Patient and carer satisfaction in geriatric day hospitals. *Disability and Rehabilitation*. 17:252-255

Stobie M (1999). *Respite Survey*. Aberdeen: Report to Joint Community Care Planning Group for Physical Disability.

Strang VR (2000). Caregiver respite: coming back after being away. *Perspectives*. 24: 4;10-20

Strang VR, Koop PM & Peden J (2002). The experience of respite during home-based family caregiving for persons with advanced Cancer. *Journal of Palliative Care* 18:2; 97-104

Tester S. (1999) Useful services for families: Research findings and direction. *International Journal of Geriatric Psychiatry* 14; 165-181

Valkenier BJ, Hayes VE & McElheran (2002). Mothers' perspectives of an in-home nursing respite service: Coping and Control. *Canadian Journal of Nursing Research* 34;1; 87-109

Zarit S H, Gaugler J E & Jarrott SE (1999) Useful services for families: Research findings and direction. *International Journal of Geriatric Psychiatry* 14; 1

