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Evidence Check

Best practice in caring for carers

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Best practice in caring for carers: an Evidence Check rapid review

Contents

1 Executive summary

The primary aim of this report was to find and determine the characteristics of interventions that enabled carers to gain access to services that would improve their health and wellbeing.

Care coordination programs were the only type of intervention that showed evidence of improving carers' access to services. A Cochrane systematic review of case management of dementia patients provided limited evidence for increased service use and uptake, and moderate evidence for improved health and wellbeing for carers. The review discussed the merit of providing support to research that investigates the effectiveness of those models of care coordination that are provided to people with dementia and which directly involve carers. In those models, however, carers' needs were often secondary to those of the care recipient. Considering this, we do believe this model of care could be effective for carers who support people with needs other than those of dementia patients.

There was no good quality evidence provided for improving carer access through primary care interventions. We found only one government-funded systematic review with an additional supplementary report and a peer-reviewed publication, all published by the same authors and identifying six government-funded demonstration projects. The three reports discuss a number of measures to overcome barriers in accessing services for carers, including tagging records, providing flexible service delivery through allowing self-referrals by carers and same day appointments, administering wellbeing checks for new or older persons, and asking people if they are a carer as standard procedure when they enter the practice. However, the projects were all completed between 1995 and 2002 and provide limited information. For example, no data are provided on any of the measures described within the projects. Information discussed within this report is based on the authors' evaluation of the projects. Given their direct relevance to the review, a summary of the six projects has been included in the report.

The vast majority of the data collected was from qualitative studies that discussed factors which prevent access to services. Factors reducing uptake of services included cultural values, carer beliefs, poor communication with health service providers, inflexibility in services, appropriateness and quality of care, and poor access to information. There were also a number of alternative methods identified which could improve delivery of programs including telephone- or web-based access to programs that have previously been individual or group-based, although the latter are still necessary to maintain a flexible approach to delivering programs.

Based on the information from this rapid review a number of recommendations are provided:

1. Due to the lack of high-quality trials there is a need to determine what interventions would improve carers' gaining access to services
2. Studies undertaken should include ethnic minority groups and assess how their needs may differ from those of the mainstream population
3. The need for improved modes of information provision to carers to improve knowledge of what services are available and how to access them, resulting in carers being able to make informed decisions on how best to carry out their caregiving role
4. Training of health care providers on communication skills to recognise the caring role, recognise young carers and effectively communicate end of life issues would be beneficial.

2 Introduction

Access to services is a complex area of health service delivery. Optimal access to health care is frequently defined as 'providing the right service at the right time in the right place'.[1] However there is a distinct difference between 'having access' which is based on the adequate supply of services, programs and systems to facilitate utilisation, compared to 'gaining access', which relates to the entry to, or actual utilisation of these services.[2] Indeed, even when services do exist, issues such as affordability, physical accessibility and acceptability can reduce their use by patients. In addition, social or cultural obstacles, and differing assumptions and expectations in relation to accessing services can restrict service uptake.[2]

Informal carers are a particularly vulnerable group. There is a substantial body of evidence that indicates a carers' health and wellbeing are significantly worse than their non-caring counterparts.[3-5] This has prompted a range of services to be available for carers including but not limited to respite service, adult health checks, pharmacology interventions, counselling, education and training, coping skills programs, and psychology programs.[6-9] Despite these services being available, carers underutilise these services.[10]

The NSW Carers Strategy 2014 – 2019 is being implemented by government organisations, non-government organisations and private businesses in new partnerships designed to deliver better services and support for carers.[11] Focus five of the strategy is to improve the evidence base so that policy and practice for carers is informed by quality evidence. This report has been commissioned by the NSW Ministry of Health (Integrated Care Branch) to inform a range of potential future activities, including development and direction of relevant policy and programs. The Integrated Care Branch has requested an Evidence Check to summarise what is known about best practice service provision for carers in accessing care for their own health and wellbeing. A priority interest is models of care that potentially facilitate and support an option for carers to access services for themselves at the same time as accessing services for the person they are accompanying. Therefore the primary aim of this report was to determine the effectiveness of interventions, models and/or frameworks that enable carers to gain access to services to improve their health and wellbeing. Secondary aims were investigated wherever evidence was available. Those aims included the types of services, and the types and timing of access to these services, that carers want for themselves; factors that influence carers' use/uptake of health care services for themselves; difference in effectiveness outcomes for population sub-groups; and whether the effectiveness of outcomes for models of care for carers depends on the point-of-service contact (e.g. general practice, community health, tertiary or specialist referral).

3 Methods

A description of the method is given below. Appendix 1 provides greater detail of the search strategy.

A comprehensive search of the Medline database, PubMed and The Cochrane Central Register of Controlled Trials (CENTRAL database), was undertaken for systematic reviews studies between 2010 and 2015. Only the last five years of systematic reviews were searched, as they would have included any relevant prior information from previous years. Clinical trials (quantitative, qualitative and mixed methods original investigations) were included in the search between 2005 and 2015. Participants in the studies were carers, defined by the NSW Ministry of Health as an individual who provides unpaid and ongoing support for another person due to disability, chronic, terminal or mental illness, dementia or ageing. Search terms included within the title or abstract included caregiver*; care-giver*; carer*; family*; families*; Caregivers/. As there were no interventions that were defined and the aim of the review was to determine what would work to increase uptake of services, a broad search was used. These included search terms combined with the carers terms in the title or abstract for support*; access*; utilis*; utiliz*; service*.

Studies were included if they were in English, full texts were available, and a priority focus was placed on articles from Australia, New Zealand, Canada and United Kingdom. Articles from low- and middle-income countries were excluded.

Based on the search there were 1905 systematic reviews and 3143 original investigation hits. Abstracts were read, duplicates removed (n=9) and full texts were obtained for those that were identified as being relevant to the primary aim: to determine the effectiveness of interventions that improved carers' access to services. This was defined as any intervention where the effectiveness was determined through the proxy measure of use of services (quantitative measure), for example an increase in primary care visits and uptake of services. Reference searches were completed on all potential studies and expert opinion was sought for additional publications. A total of 105 systematic reviews and 57 original investigations were identified as possible inclusions.

Because the focus of this review is on interventions that influence carers' access to services, rather than on the effectiveness of interventions to improve carers' health and wellbeing, 1894 systematic reviews and 3139 original investigations were excluded from the review. Only two systematic reviews (one Cochrane systematic review; one government funded literature review)[12,13] and two original investigations[14,15] remained which informed the primary aim of this review. For the primary aim, an additional grey literature review, which was government funded[16], and three peer-reviewed publications[17-19] were included as they were directly relevant and found through alternative search methods (reference searches and expert opinion).

For the secondary aim, the systematic reviews were searched on an ad hoc basis; fourteen systematic reviews[20-33] were identified during the search. These items were not found through systematic searches.

Although not discussed in this report, additional information has also been flagged in Appendix 2. These include recently funded projects that have not been completed and reports that are not directly relevant but may be of interest to the NSW Ministry of Health.

4 Interventions to improve access

This section discusses models, frameworks or initiatives that enable carers to gain access to services. Information from the retrieved studies has been grouped into two sections below: primary health care and care coordination interventions.

4.1 Primary health care interventions

Given the evidence of the poor health and wellbeing of carers, access to primary health care is vital. When carers are identified through having systems in place to tag their records, there is the potential to reduce a major barrier in gaining access to primary care, as so often people are not recognised as caregivers when they present to GP clinics.[34]

Although out of the date scope of this Evidence Check there was one government funded systematic review with a supplementary report, and one peer-reviewed publication, which described the evidence for carers' access to primary health care facilities.[13,16,19] These were included at the request of the funding body. All three articles report on the six demonstration studies.

Interventions to improve access to primary care for caregivers are typically targeted at professional factors (such as focusing on the care recipient, and/or overlooking or being unaware of the responsibility of carers), service issues (such as rigid service delivery and long waiting times), language or cultural barriers (including absence of interpreters, inequality in treatment through stereotyping and prejudices, and lack of understanding of cultural and religious differences), care or care recipient factors (such as reluctance to seek or accept help and time burdens), and/or carers' information and knowledge gaps (including lack of information about suitable services and not knowing how to correctly carry out caregiving tasks).[13,19] Past research has attempted to address these barriers to access in three different ways: through interacting with carers, liaising with GP practices, and collaboration with primary care groups or trusts. One British scheme, Advanced Access, has been shown to have benefits for carers by addressing General Practitioner (GP) practice operations, through reorganising the workload, assessing appointment systems, and reconciling patients who want to pre-book appointments and those who do not.[13,35]

In these reports six government funded demonstration projects were identified that assessed primary care interventions for carers.[13,16,19] These were UK-based projects completed between 1995 and 2002 and with the exception of one they all focused on the general population. Each project has only a summary of the intervention and a description of the barriers and strengths. It is therefore difficult to determine the effectiveness of the projects, and information presented in the rest of this section (4.1) is based on the discussion and conclusions provided by the authors.

All studies recognised that GPs need training to become more attentive to caregivers' needs, and that when the primary care team receives training and support, staff become more conscious of and responsive to carers' issues.[19] For example one study was a quantitative analysis of the Cornwall Carer Support Workers Service, and found that through additional support and training GPs were more likely to consider the caregiver as an aid in successful patient care, and focus holistically on both patient and caregiver needs.[13]

All six papers also identified a number of measures to overcome barriers to accessing services for carers, such as tagging records, providing flexible service delivery through allowing self-referrals by carers and

same-day appointments, administering wellbeing checks for new or older persons, and asking people if they are a carer as standard procedure when they enter the practice.[13,19] For instance the Hackney and Newham GP–Carers Project (1992–1995), a mixed methods study on the amount and quality of support that carers receive from their GP, particularly focussed on a health check system for carers of elderly people with mental illness. Carers were tagged on the computer system and offered the additional health check, which addressed each carer's health, caring situation and the concerns about the person they were caring for. Of the eleven carers who were interested in these checks, only seven attended them. The authors reported that carers thought the appointment system was beneficial, that they felt reassured by the practice's commitment to them, and that being recognised as a carer was important.[19]

A key factor in primary care access is caregivers' perceptions of their role and responsibilities. Often carers are patient-focused and their only contact with their GP is for patient needs and concerns.[13] Through surveys and consultations with carers in the Hackney and Newham GP-Carers Project to ascertain what support they required from their GP, good practice guidelines were established which encouraged GPs to speak with caregivers about their needs and self-care and how to best manage caregivers' needs in a primary care setting.[13,19] Additional interventions to make the most out of caregivers' contact with primary care services have included medical receptionists offering carers information resources when they attend the clinic for care-recipient appointments, and telephone or web-based methods which allow communication with primary care staff from home or remote locations when it is needed.[13]

Carer information resources such as information packs and service directories have been initiated by a number of the studies included in the reviews, in order to overcome caregivers' knowledge gaps in regards to health care and health services.[19] A member of the primary care team was assigned responsibility for keeping the information current and distributing the packs to carers when they visited the practice, whether it is for their own or their care recipient's appointment.[13,19]

No interventions have been identified to address language and cultural factors, and as such these remain a barrier to primary care services for carers. Only one study, the Brent Primary Care Project, mentioned the need to try and improve access for ethnic groups; recommendations were made to contact such groups through attending places of worship, local shops, and post offices, however nothing was implemented.[19]

The author of these systematic reviews made a point of mentioning that most of the interventions both recommended and implemented by these studies provided only preliminary evidence, with a need to substantiate this work before any major changes were implemented.

4.2 Care coordination interventions

"Care coordination is the deliberate organisation of patient care activities between two or more participants (including the patient) involved in a patient's care to facilitate the appropriate delivery of health care services. Organising care involves the marshalling of personnel and other resources needed to carry out all required patient care activities, and is often managed by the exchange of information among participants responsible for different aspects of care".[36]

Carers may also benefit directly from care coordination if it targets the specific aims of a program toward them, thus impacting on their use of services, health and wellbeing, and access to support and information. Indirectly, carers may also benefit in their quality of life and health and wellbeing if there is an uptake of services such as respite and day care by the care recipient.[12]

Care coordination can take many forms but the most common services include:

- Patient care including home care (support with general domestic tasks and with self-care), day centres (support with leisure activities), home-delivered meals, and respite care (a short break away from the carer)
- Health service patient interventions such as nursing, counselling, occupational therapy, aids to mobility and mental health care
- Involvement of the voluntary sector for patient and carer, which may offer information, telephone help lines, befriending and carers' support groups.[12]

Overall, there was one systematic review, which included the four original peer-reviewed publications found in our search, discussing care coordination programs that directly involved and/or looked at improved outcomes for carers.[12,14,15,17,18] All of these programs involved dementia patients as the care recipient. A Cochrane systematic review (2015) evaluated the effectiveness of case management approaches to home support for people with dementia, from the perspective of the different people involved including patients, carers, and staff.[12] Only randomised controlled trials (RCTs) were included. Case management (a broader approach to care coordination) was defined as any intervention delivered in the community (i.e. not in hospital or residential care settings) which used a human service professional (typically a nurse or social worker) to arrange and monitor an optimum package of long term care services. Of the 13 studies in the review, only two reported on health service use by carers and nearly all on the health and wellbeing of the carer. As a proxy measure for carers' utilisation of services, the number of visits to services by the carer including health services, or uptake of respite for patients, are often used. Case management resulted in significantly few hospitalisations and emergency visits over a three year period by the carer (Newcomer-US study).[12] However, there were no differences for carers in their primary care use, physiotherapist appointments, geriatric/psychiatrist consultations, and medical specialist appointments (Jansen - Netherlands).[12]

In addition, the review found that in some studies at 18 months, case management was more effective than usual care in providing access to support in the form of home care use, information services, and carer support groups. When case management was implemented for 12 to 18 months, there was an increase in the number of services used by patients in the case management group, including home care, day care, respite care, domestic paid helpers, and personal care. Carers also experienced better quality of life, improved social support, and were more satisfied with the quality of care received for their care recipients. Overall, this review found that, at certain time points after initiation of case management, some data indicated improved outcomes for patients and carers. For carers, these data had both direct (e.g. improved quality of life) and indirect (e.g. satisfied with care recipients care plan) impacts. However, the interventions varied considerably in areas such as the content of case management interventions; target populations; skills mix of those providing the case management; degree of control and influence over allocation of care resources; and intensity and duration. Therefore there was no one aspect of care that was common across the intervention and which could be considered an effective approach. Specific details of each intervention are provided in Appendix 3.

The four original peer-reviewed articles have not been described here, as they were included as part of the thirteen articles within the Cochrane review.[14,15,17,18]

5 Carers' use and uptake of services

There are a number of factors that influence a carer's uptake and use of services available to them. A Health Technology Assessment[22] from 2009 assessed quantitative and qualitative evidence for the effectiveness of respite in improving the wellbeing of informal carers, which included reasons for utilising or not utilising respite care for the care recipients.[22] Qualitative synthesis found that the amount and flexibility of respite, and the appropriateness and quality of care, are important factors in alleviating carer depression.[22] Interestingly, there is an assumption that if carers receive support through respite then there would be improvements in wellbeing enabling further care, ultimately resulting in a reduced need for institutionalisation. However, this meta-analysis found increased rates of institutionalisation in respite users both in the short term (six months) and the longer term (12 months).[22] This is likely the result of respite being used as a last resort for those individuals who are already at a stage where being institutionalised is not far away. The qualitative component of this review discusses the notion that many of the attitudes preventing early use of respite are not only the result of cultural values or carer characteristics but also from poor knowledge of the availability and content of respite programmes, and from the need for better information provision concerning entitlements and availability of services.[22] Barriers related to language and culturally held beliefs also prevented access or appropriate care being implemented.[19] These factors are also addressed in other reviews.[19,23,29,30]

A systematic review looking at differences in rural and urban carers found surprisingly little difference in carers' service use.[27] Within the review only two papers were found that compared service use; one showed little difference and the other found that urban carers utilised more services. However, the latter paper found that these differences were attributable to carers' attitudes and beliefs and to the care recipients' evaluation of service delivery, rather than to income or geographic location.[27] Thus, further highlighting that attitudes and beliefs of carers influence their uptake of services.

In addition to the factors above, communication with health professionals was cited as an important aspect of care, yet was an ongoing barrier for many carers accessing health services. Carers felt that health service providers:

- Failed to recognise their caring role
- Did not recognise young carers
- Prioritised the care recipient over the needs of the carer
- Were not aware of the needs and issues of caregiving
- Did not communicate effectively on end-of-life issues.[19,23,29]

Education and training of health professionals in improving communication is a potential way to alleviate these issues, however, only those studies identified in Section 4.1 have addressed this issue.[13,19] Overall, there is scarce data available to see whether this would result in improved access to health services.[19,23,29]

Access to information and support was a commonly cited barrier to accessing services. Not knowing what services were available and how to access them were ongoing factors that resulted in reduced uptake of already-existing services.[22] In addition, lack of access to information and support about their care recipient's disease (e.g. diagnosis, treatment, stages and symptoms) and their legal and financial planning were also cited as stressful.[30]

6 Alternative methods of delivering programs

There is substantial information on services, programs and interventions that are provided to carers to improve their health and wellbeing.[4,33] Interventions to improve health and wellbeing can be grouped into three main categories:

1. Educational, which address caregiver mastery and preparedness
2. Psychosocial, which focuses on coping, relationship issues, and problem-solving strategies
3. Self-care, to promote caregiver health and wellbeing.

Each of these categories can be targeted as single interventions or as multi-faceted interventions to support carer health and wellbeing. A recent meta-analysis on determining the effectiveness of interventions for family caregivers of older adults found multi-faceted interventions had a significant effect on carers' burdens compared to single interventions. This highlights the importance of combining interventions for holistic health and wellbeing.[37] However, access to programs is often hindered by lack of time, transport, and not being able to leave their care recipient alone, resulting in alternative methods of delivering these services. Therefore, carers can choose the method that works best for them, with the ultimate aim of increasing uptake to these services. A literature review about informal caregivers of hematopoietic cell transplant patients discussed creative educational approaches to improve the uptake of interventions available to carers. A summary of these methods of delivery with their associated advantages and disadvantages are provided in Table 1.

Despite the number of alternative methods for carers to access information, there is still a long way to go to determine if these interventions are effective in improving the health and wellbeing of carers. Although many of the interventions have been trialled, they are of poor quality due to poor research design, low sample sizes, and lack of control groups.[20,21,24-26,28,31,32] In addition, there are many different designs of these interventions including duration, number of times engaging with the intervention, who delivers the intervention and the resources provided in the intervention. However, given that many carers want flexible delivery in information and that no 'one size fits all' approach will be effective, this may be beneficial for this population. Appendix 4 provides a table of the outcomes for interventions that use the modalities outlined in Table 1.

Table 1: Interventions to improve access to information and support[38]

Intervention modality	Advantages	Disadvantages

Telephone-based strategies
    Telephone contact
    Computerised phone support
	Daily interaction and support with professionals and/or laypersons	Poor response time unless this is built into the system
		
		Computerised support impersonal

Web-based strategies	Convenient Access online support provided anytime (24/7)	Need skills to navigate the internet

Intervention modality	Advantages	Disadvantages
Individual sessions	One-on-one interaction to address specific needs	Labour intensive
Group sessions	Offers support of others to normalise the situation	Not helpful for those who have difficulty sharing in a group setting

7 Discussion and conclusion

The primary aim of this report was to determine the characteristics of interventions, models and/or frameworks which enable carers to gain access to services to improve their health and wellbeing. The best available evidence for improving access is through care coordination programs.[12]

A recent Cochrane review of case management of dementia patients provided limited evidence for improved service use and uptake, and moderate evidence for the health and wellbeing of carers. Although there is not enough evidence to firmly support care coordination, it is certainly promising. Care coordination also improved many of the factors that carers cite as barriers to services such as lack of information, lack of knowing about services and improved communication. Based on the Cochrane authors' assessment of risk of bias in the two studies directly discussing carer service utilisation, Jansen, Netherlands 2011, was assessed as medium-risk and Newcomer, US 1997–2005 (multiple studies on the same program) as high-risk. Indeed as there are only two studies discussing carer utilisation, limited conclusions can be drawn. For improvements in carers' quality of life at 12 months (five studies: Chien, Hong Kong 2008; Chien, Hong Kong 2001; Jansen, Netherlands; Vickrey, California; Lam, Hong Kong) it was considered to be of moderate evidence (GRADE assessment) with further research likely to have an important impact on the confidence of the estimate of effect and may change the estimate.[12] For improvements in carer burden at 10–12 months (seven studies: Chu, Canada; Lam, Hong Kong; Newcomer, US; Chien, Hong Kong 2008; Chien, Hong Kong 2001; Jansen, Netherlands; Eloniemi-Sulkava, 2001) the quality of evidence was low, suggesting further research is very likely to have an important impact on the confidence in the estimate of effect and is likely to change the estimate.[12]

From a policy-maker's perspective this review highlights that, although promising, there is not yet a robust evidence base to support case management in meeting the needs of patients with the inclusion of their carers in this model of care. Yet, there is merit in providing support to research that investigates the effectiveness of models of case management for people with dementia and including their carer in the management plan. It is possible that the broader area of case management within care coordination could also support individuals without dementia and their carers, although further investigation into the effectiveness of these models for different diseases is warranted prior to implementation.

Quality assessment for the interventions in Section 4.1 Primary health care interventions was not completed. Those publications were small, government-funded demonstration projects that did not fall within the date scope for inclusion in this Evidence Check.[13,16,19] In addition, there is limited information provided in the studies to determine how effective the projects were. The information provided in this report is based on the authors' discussions and conclusions. Given their direct relevance to the review a summary of the projects has been included in this report.

For the secondary aim the data collected were qualitative studies that discussed factors that prevent access to services. Many of these were reviews which set out to find empirical evidence on the effectiveness of programs, but searches did not reveal any evidence, or indeed the few that did found the research to be of poor quality.[23,29] We did not complete a quality assessment of these reviews.

Lastly, there are a number of alternative ways that have been identified that could improve carers' access to programs that are already available. These include telephone- or web-based access for programs that have previously been individual or group based. Although the latter are still preferable to some carers, flexible delivery of programs is important for this cohort.

Based on the information provided on this topic there have been a number of recommendations cited within systematic reviews that are relevant. They are:

1. Due to the lack of high-quality trials in this area there is a definite need to determine what interventions would improve a carer's access to services. This should also include whether there is adequate provision of services, what services are being used and how others can be improved

2. Studies are needed that address the optimum time point for provision of services that relieve carer burden and determine what interventions would break down barriers to the use of services Many services are utilised too late to support carers. Information on how to get carers to access these services earlier would be beneficial

3. Studies should include ethnic minority groups and assess how their needs may differ from the general population

4. The need for improved modes of information provision to carers. There are many studies that identify barriers to accessing information for carers that would directly and indirectly result in improved health and wellbeing. Without the knowledge of the availability of services and how to access them, carers cannot make informed choices of how best to carry out their caregiving role. It is an issue for care provision of how to identify and inform carers of the availability of services. Research is needed into how to improve communication of service availability to carers

5. Training of health care providers. Quality of care was an important issue for carers and a number of reviews highlighted poor skills of care staff in providing information and support to carers and acknowledging their roles in care. Education and training for health professionals in communication skills to recognise the caring role, to recognise young carers and to effectively communicate end of life issues would be beneficial.

Based on this rapid review, there is little or no evidence of the effectiveness of interventions to improve access for carers to health services. Due to the lack of programs, interventions and models of care available in improving access, the NSW Ministry of Health is in a good position to trial and evaluate new models of care that could have significant impact on carers' access to services, ultimately improving their health and wellbeing.

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9 Appendices

9.1 Appendix 1: Search terms

PubMed search strategy

Order #	Search terms	Hits
1	Search Caregivers/	39541
2	Search families*[Title/Abstract]	176123
3	Search family*[Title/Abstract]	582130
4	Search carer*[Title/Abstract]	8881
5	Search care-giver*[Title/Abstract]	2005
6	Search caregiver*[Title/Abstract]	35455
7	1-6 OR	729124
8	Search ((utilis*[Title/Abstract]) OR utiliz*[Title/Abstract])	399871
9	Search access*[Title/Abstract]	320070
10	Search support*[Title/Abstract]	1044813
11	service*[Title/Abstract]	351523
12	8-11 OR	1928430
13	7 AND 12	142984
14	13 AND Filters: Systematic Reviews; published in the last 5 years; Humans; English	1415
15	13 AND Filters: Clinical Trial; published in the last 10 years; Humans; English	3143

The Cochrane Central Register of Controlled Trials (CENTRAL database) search strategy (including Database of Abstracts of Reviews of Effects [DARE])

Order #	Search terms	Hits
1	caregiver* or (care next giver*) or carer* or family* or families* Filter: Cochrane reviews only	334
2	MeSH descriptor: [Caregivers] explode all trees	1281
3	1 OR 2	490

9.2 Appendix 2: Additional material

9.2.1 Study of interest

Dr Lyn Phillipson. The development and trial of an innovative community-based Respite Action Intervention for carers of people with dementia. (2014 Resthaven Inc. Dementia Research Award)

The provision of respite is consistently identified by carers of people with dementia as one of their critical unmet care needs. Despite this, the overall proportion of carers of people with dementia who use available respite and other support programs tends to be low. In Australia this is likely to be the result of numerous factors including informational, attitudinal and service-related barriers. The Respite Action Intervention for carers of people with Dementia (RAID) is an innovative multicomponent community intervention that will utilise education, social marketing, and state-of-the-art technologies, embedded in an interactive, local services website to improve carer knowledge, attitudes and uptake of respite services, to meet their need for 'more than just a break'. (http://dementiaresearchfoundation.org.au/researchers/lyn-phillipson)

Detailed project summary:

The Respite Action Intervention for carers of people with Dementia (RAID) is an innovative multicomponent community intervention. RAID utilises a comprehensive social marketing approach to supporting behaviour change through:

- Improving carer knowledge of local respite services – through the development of a local service and respite pathway, and promotion to carers via a local interactive website (Dementia Online Illawarra)
- Promoting positive attitudes towards the benefits of the use of respite services – through the use of persuasive respite promotional messages via multiple media and interpersonal communication channels (e.g. marketing campaign, education sessions, carer support groups, and referral by General Practitioners (GPs) and Practice Nurses (PNs)
- Providing practical and emotional support for respite service use – through the improved referral behaviours of GPs and PNs, use of the website, and the normalisation of respite use by service providers and other carers of people with dementia.

A quasi-experimental design will be utilised to evaluate the impact of RAID to improve carer knowledge, attitudes and uptake of respite services. Evaluation will include measuring the program impact by a carer survey, as well as the monitoring of inputs and outputs to establish the reach and participation of carers and service professionals in the program.

9.2.2 Reports of interest

1. Evaluation of Alzheimer's Australia Services to Improve Access for Special Needs Groups. Available from: https://fightdementia.org.au/sites/default/files/20120813_SALO_AlzAustFinal_EvaluReport_Nov 2011.pdf

This evaluation reports on the achievements of 11 Service Access Liaison Officer projects implemented by Alzheimer's Australia to improve access to dementia services for specific needs groups. The projects, which have been implemented in all states and territories, have focused on the needs of Aboriginal and Torres Strait Islander people; people from Culturally and Linguistically Diverse backgrounds (CALD); Gay, Lesbian, Bi-Sexual, Transgender and Intersex people (GLBTI); people with Younger Onset Dementia (YOD); and people in rural and remote locations (R & R). Relevant literature has been reviewed to identify issues for specific groups and work is being undertaken to address these issues.

2.   Training and Supporting Carers: The National Evaluation of the 'Caring with Confidence' Programme. 2011. Available from: http://www.york.ac.uk/inst/spru/research/pdf/CWC.pdf

The Caring with Confidence (CwC) programme aimed to provide support to 37,000 carers in England. It was the largest programme of training for carers ever planned in the UK, with a total budget of £15.2m over three years. It aimed to provide training and support to carers, with the objective of giving them greater choice and control in important areas of their lives such as health, access to social care support and the ability to manage paid work or other activities alongside their caring role. It was anticipated that carers would benefit through improved health and well-being, greater levels of independence, and more time outside caring, which in turn would be of value to those they care for. This report discusses the national evaluation of the program.

3.   Cass, B, Hill, T, and Thomson, C. Care to Work? Expanding choice and access to workforce participation for mature aged women carers. 2012. Available from: https://crawford.anu.edu.au/public_policy_community/content/doc/Cass%20paper%2028-11.pdf

This report aims to explore policies to enhance mature aged women's participation in the labour market, with a particular focus on fostering employment choices for women with current or past informal caring responsibilities.

The report discusses the possibility of a 'Carer Card', which would be provided to a carer at the first point of contact with health, aged care or disability services, to link carers to support options. The Carer Card would include a carer's assessment encompassing:

- An inventory of specific care needs and the care situation
- Links to formal and informal supports.

The aims of the proposed card included verifying the relationship between carer and care receiver, and it was proposed that it could be used as a replacement concession card and also as a discount card.

4.   Care Provision within Families and its Socio-Economic Impact on Care Providers Report for the European Commission DG EMPL Negotiated Procedure VT/2007/114. 2009. Available from: http://socialwelfare.bl.uk/subject-areas/services-activity/social-work-care-services/spru/135064EUCarers09.pdf

The growing EU recognition of the importance of informal and family care-giving provided the context for this study. The aims of the study were to compile evidence for:

- The prevalence of long-term (informal) care-giving within a family setting to dependent family members or relatives in various EU countries, including recent and anticipated trends. The study was to focus on the most 'heavily burdened' carers – those involved in intensive care-giving or without additional support
- The socio-economic impact of caregiving on the households of family carers. The study was to focus on the most 'heavily burdened' carers, paying particular attention to gender inequalities in care-giving and their consequences
- Measures aimed at alleviating burdens on family carers by supporting them in the provision of care and/or compensating for the adverse socio-economic consequences of care-giving.

9.2.3 Website
Care Coordination. Agency for Healthcare Research and Quality, Rockville, MD. 2015. Available from: http://www.ahrq.gov/professionals/prevention-chronic-care/improve/coordination/index.html

A government website that provides information on care coordination and continuous quality improvement processes.

9.2.4 Information booklet

Cornwall Council: Services for adult carers. Available from:
http://www.cornwallcarers.org.uk/downloads/carers_information_pack_2012.pdf

A 36-page booklet that provides information for a range of services available for carers.

9.3 Appendix 3: Interventions for care coordination

Summary of types of interventions for care co-ordination by country and year[12]

Coordination program				
Country; Year	Skill mix	Case management tasks	Components	Breadth of services
1. US; 2003-2011 (multiple studies)	Care consultation	Assessment, care planning, implementation and monitoring of care plan	Participant information and education, participant advocacy, provision of emotional support, carer education. A standardised protocol was followed by care consultants	Case manager coordinates/liaises with other outside services
2. US; 2004-2011 (multiple studies)	Led by their primary care physician and a geriatric nurse practitioner who served as the care manager	Case finding, assessment, financial assessment, care planning, implementation and monitoring of care plan, arranging/allocation of services, review, case closure	Participant information and education, emotional support, carer education, medication management, education on communication skills; carer coping skills; legal and financial advice; participant exercise guidelines with a guidebook and videotape; and a carer guide provided by the local chapter of the Alzheimer's Association	Case manager coordinates/liaises with other outside services, within multidisciplinary team and arranges and allocates services
3. Hong Kong; 2001	Nurse case manager	Assessment, care planning, implementation and monitoring of care plan	Participant information and education; carer education; provision of emotional/therapeutic support	Case manager coordinates/liaises with other outside services, within multidisciplinary team
4. Hong Kong; 2008	Case managers	Assessment, care planning, implementation and monitoring of care plan	Carer education	Case manager coordinates/liaises with other outside services, within multidisciplinary team

Coordination program				
Country; Year	Skill mix	Case management tasks	Components	Breadth of services
5. Canada; 2000	Case managers (a social worker and an occupational therapist) and professionals such as an occupational therapist, nurse, social worker were involved as appropriate	Care planning, implementation/management of care plan, arranging/allocating services, monitoring the implementation of the care plan	Participant information and education, participant advocacy, legal/insurance/benefits/financial assistance, provision of emotional/therapeutic support, counselling/therapy	Case manager coordinates/liaises with other outside services, within multidisciplinary team, arranges and allocates services and manages care network
6. India; 2008	Time health care advisors (HCAs), two psychiatrists and a lay counsellor	Case finding, implementation and monitoring of care plan. The HCAs referred people back to the psychiatrist, or advised the families about services	Medication management, counselling, carer education, legal advice	Case manager works within multidisciplinary team, coordinates outside services
7. Finland; 2001	Delivered by a care coordinator (registered nurse) who had access to the physician	Assessment, care planning, implementation/management of care plan, arranging/allocating services	Participant information and education, participant advocacy, provision of emotional/therapeutic support, counselling/therapy, carer education	Case manager coordinates/liaises with other outside services, within multidisciplinary team, arranges and allocates services and manages care network
8. Finland; 2009	Delivered by the family care coordinator who was a trained public health registered nurse	Case finding/screening, assessment, care planning, implementation/management of care plan, arranging/allocating services	Participant information and education, participant advocacy, pharmacy/medications review/management/prescribing, provision of emotional/therapeutic support	Case manager coordinates/liaises with other outside services and coordinates/liaises with geriatrician, arranges and allocates services, does not manage care network

Coordination program				
Country; Year	Skill mix	Case management tasks	Components	Breadth of services
9. UK; 1995	Multidisciplinary team: consultant psychiatrist of old age, clinical psychologist, and where possible a community psychiatric nurse, psychiatric social worker and occupational therapist	Assessment, care planning, implementation/management of care plan, arranging/allocating services, case closure	Provide participant information and education, pharmacy/medications review/management/prescribing, provision of emotional/therapeutic support, carer education	Case manager coordinates/liaises within multidisciplinary team and with other outside services, arranges and allocates services
10. Netherlands; 2007-2011 (multiple studies)	Intervention was delivered by a case manager; nurse	Assessment, care planning, implementation/management of care plan, arranging/allocating services, monitoring the implementation of the care plan	Provide participant information and education, carer education, provision of emotional/therapeutic support	Case manager coordinates/liaises with other outside services, arranges and allocates services
11. Hong Kong; 2011	Intervention was delivered by occupational therapist who liaised closely with psychogeriatricians or geriatricians	Assessment, care planning, implementation and monitoring of care plan, arranging/allocation of services, monitoring the implementation of the care plan, review, case closure	Participant and carer education/advice, medication reviews	Case manager coordinates/liaises with other outside services, within multidisciplinary team and arranges and allocates care/services but does not manage care network

Coordination program				
Country; Year	Skill mix	Case management tasks	Components	Breadth of services
12. US; 1999-2005 (multiple studies)	Each site agency implemented the demonstration in somewhat different way	Assessment, care planning, implementation/management of care plan, arranging/allocating services, case budget management/budget holding; monitoring the implementation of the care plan. Case management was largely oriented to assessment, client monitoring, care planning, and situational problem-solving	Provide patient/carer information and education; provision of emotional/ therapeutic support, counselling, carer education	Case manager co-ordinates/liaises with other outside services, within multidisciplinary team, arranges and allocates care/services and manages care network. One element ignored by this demonstration was the co-ordination of case manager and primary care physician activities
13. US; 2006-2009	Care managers were mainly social workers	Case finding/screening, assessment, care planning, implementation/management of care plan	Carer education and co-ordination between organisations and agencies. The care managers were responsible for coordinating care and making referrals	Case manager coordinates/liaises with other outside services and within team, arranges and allocates services and manages care network.

9.4 Appendix 4: Improving access to information and support

Interventions that use alternative modalities to improve access to information and support

Country; Year	Study aims	Care recipient group	Intervention modality	# meeting inclusion criteria	Conclusions
1. Kinnane NA , Milne DJ; 2010[31]	The effectiveness of caregivers' use of the internet as a mode of information and support	Cancer	Web-based (searching for information, support groups, emails)	20	There is not enough evidence to reach any firm conclusions, however the internet is considered an accessible coping mechanism for caregivers that provides to–date information, peer support, and a means of communicating with health professionals
2. Atherton H, Sawmynaden P, Meyer B, Car J; 2012[24]	The effectiveness of using emails for healthcare appointments for scheduling, rescheduling, cancelling and reminding	Primary, secondary, tertiary and community care patients	Web-based (emails)	0	High quality studies on the effectiveness of emails for appointments are recommended, as they have the potential to increase access for caregivers
3. Atherton H, Sawmynaden P, Sheikh A, Majeed A, Car J; 2012[25]	The effectiveness of emails for communicating between patients, carers and health professionals	Primary, secondary, tertiary and community care patients	Web-based (emails)	0 (quan); 9 (qual)	Not possible to determine the effectiveness of emails as a means of communication, as studies were of low quality and had missing data. Emails have the potential to increase contact with health professionals
4. Rietdijk R, Togher L, Power E; 2012[28]	The effectiveness of telehealth interventions to support family caregivers of patients with traumatic brain injury	Traumatic brain injury	Technology-based (telephone, websites and video conferencing)	24 reporting 16 studies including (7 RCTs)	Evidence is preliminary, however telehealth services could increase access for rural caregivers due to the ability of those interventions to reach remote communities

Country; Year	Study aims	Care recipient group	Intervention modality	# meeting inclusion criteria	Conclusions
5. Godwin KM, Mills WL, Anderson JA, Kunik ME; 2013[20]	The effectiveness of technology-based treatments for carers of people with dementia	Dementia	Web-based (discussion forums, video messages, online encyclopaedia)	8 (4 RCTs)	Inadequate evidence to reach any conclusions about the effectiveness of these interventions. Technology-based interventions have potential due to their convenience and flexible delivery
6. Davies A, Rixon L, Newman S; 2013[32]	Qualitative studies of telecare for people with social care needs and their caregivers	Social care needs	Telecare (passive sensors, medication dispensers, calendar clocks)	7	The effectiveness remains unclear due to variation in the type of telecare intervention. Potential to reduce the time spent caregiving and improve caregivers' work performance
7. Boots LM, De Vugt ME, Van Knippenber RJ, Kempen GI, Verhey FR; 2014[26]	The effectiveness of internet treatments for caregivers of people with dementia	Dementia	Web-based (websites disseminating information and strategies and allowing communication with other caregivers)	12 (3 RCTs)	These interventions may be a valuable extension to existing care programs providing accessible support for carers, however compliance with this type of intervention has been difficult to assess and most studies overlook this variable
8. McKechnie V, Barker C, Stott J; 2014[21]	The effectiveness of computer-based interventions for carers of patients with dementia	Dementia	Computer-based (interactive DVDs, computer-telephone integration, voice response program, educational resources, emails)	16 reporting 14 studies	Mixed results due to lack of high–quality studies. Computer–based programs have the potential to reach more caregivers through at–home and mobile access, as well as having the benefit of being cost-effective.