Interventions to enhance access to and utilization of formal community care services for home dwelling persons with dementia and their informal carers. A scoping review

Røsvik, Janne; Michelet, Mona ; Engedal, Knut; Bieber, Anja ; Broda, Anja; Goncalves-Pereira, Manuel; Hopper, Louise; Irving, Kate ; Jelley, Hannah; Kerpershoek, Liselot ; Meyer, Gabriele; Marques, Maria J.; Portolani, Elisa; Sjölund, Britt-Marie; Skoldunger, Anders ; Stephan, Astrid ; Verhey, Frans; de Vugt, Marjolein; Woods, Robert; Wolfs, Claire ; Zanetti, Orazio; Selbaek, Geir; Consortium Actifcare

Aging and Mental Health

DOI:
10.1080/13607863.2018.1523876

Published: 01/02/2020

Peer reviewed version

Post-print only:

Document of Record published as:

Røsvik, J., Michelet, M., Engedal, K., Bieber, A. Broda, A., Gonçalves-Pereira, M., Hopper, L., Irving, K., Jelley, H., Kerpershoek, L., Meyer, G., Marques, M.J., Portolani, E., Sjölund, B-M., Sköldunger, A., Stephan, A., Verhey, F., de Vugt, M., **Woods, B.,** Wolfs, C., Zanetti, O. & Selbaek, G. On behalf of the Actifcare Consortium (2019). Interventions to enhance access to and utilization of formal community care services for home dwelling persons with dementia and their informal carers. A scoping review, *Aging & Mental Health*, DOI: 10.1080/13607863.2018.1523876

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Funding:

This is an EU Joint Programme - Neurodegenerative Disease Research (JPND) project. The project is supported through the following funding organisations under the aegis of JPND - www.jpnd.eu. Germany, Ministry of Education and Research, Ireland, Health research board, Italy, Ministry of Health, the Netherlands, The Netherlands organization for Health Research and Development, Sweden, The Swedish Research Council for Health, Working Life and Welfare, Norway, The Research Council of Norway, Portugal, Foundation for Science and Technology, FCT, United Kingdom, Economic and Social Research Council. The funding body had no influence in the design of the study, nor collection, analysis, and interpretation of data, nor in writing the manuscript.

Acknowledgement

The authors wish to thank all experts who participated in the study.

The ActifCare Consortium partners are:

Coordinator: Maastricht University (NL): Frans Verhey, Marjolein de Vugt (scientific coordinators, WP1 leader).

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Disclosure of interest

The authors report no conflict of interest.

Interventions to enhance access to and utilization of formal community care services for home dwelling persons with dementia and their informal carers. A scoping review.

ABSTRACT

Objectives

Home dwelling people with dementia and their informal carers often do not receive the formal care services they need. This study examined and mapped the research regarding interventions to improve access and use of formal community care services.

Method

This is a scoping review with searches in PubMed, CINAHL, PsychINFO, Medline, Cochrane Database of Systematic Reviews, Social Science Citation index and searches of grey literature in international and national databases. Studies were categorized according to the measure used to enhance access or use.

Results

From international databases, 2833 studies were retrieved, 11 were included. Five studies were included from other sources. In total, 16 studies published between 1989 and 2018 were examined; seven randomized controlled trials, six pretest-posttest studies and three non-randomized controlled studies. Sample sizes varied from 29 to 2682 participants, follow-up from four weeks to four years. Five types of interventions were identified: Case management, monetary support, referral enhancing, awareness & information focused and inpatient focused. Only two studies had access or use of community services as the primary outcome. Fourteen studies, representing all five types of interventions, had positive effects on one or more relevant outcomes. Two interventions had no effect on relevant outcomes.

Conclusion

The included studies varied widely regarding design, type of intervention and outcomes. Based on this, the evidence base for interventions to enhance access to and use of formal community services is judged to be limited. The most studied type of intervention was case management. More research is recommended in this field.

Keywords: Dementia, home dwelling, access, community care, Actifcare

Background

In Europe 10.5 million people had dementia in 2015, (Alzheimer's Disease International, 2015). This makes dementia one of the 21st century's greatest health challenges. It is estimated that the number will double in 35 years (Prince et al., 2013). Dementia leads to increasing dependency regarding activities of daily living and need for help from informal and professional carers. Many people with dementia prefer to live at home as long as possible to maintain their social network (Luppa, Luck, Brähler, König, & Riedel-Heller, 2008) and quality of life (Nikmat, Hawthorne, & Al-Mashoor, 2011), and it has been shown that use of in-home help services early in the trajectory of dementia may delay institutionalization (Gaugler, Kane, Kane, & Newcomer, 2005). Still, home-dwelling people with mild to moderate dementia and their informal carers are found to use community services, such as home support, day care and respite care, less frequently than medical services, even though these services may be highly beneficial in their situations (Weber, Pirraglia, & Kunik, 2011). A literature review showed that one third of informal carers of people with dementia does not use any formal services. The reasons given were that services were not needed (yet), lack of awareness, or that the person with dementia declined (Brodaty, Thomson, Thompson, & Fine, 2005). Other studies have found that this group often does not receive services of the type and quality they need, and that they experience difficulty in accessing home- and community-based services (Phillipson, Jones, & Magee, 2014). Identified barriers for access to and use of

care services include the stigma attached to dementia, lack of information about services, the way access to health care is organized and how services are perceived (Brodaty et al., 2005, Stephan et al., 2018). Ethnic minority groups may also face cultural and language barriers (Mukadam, Cooper, & Livingston, 2013). The research describes less facilitators than barriers. Stephan and colleges (2018) found that a health and social care professional serving as a key contact person could address major barriers in the access to and use of formal care services for people with dementia and their informal carers. Contact initiated proactively and as early as possible with people with dementia and their families, and a trusting and consistent relationship, were also facilitators (Stephan et al., 2018). These findings are in line with earlier research (Carpentier et al., 2012). The question facing national policy makers is how barriers to access can be overcome and how facilitators to access can be utilised. There is a need for information about interventions that have been used to enhance access, and the nature of the evidence base they represent.

The present scoping review constitutes a part of The Actifcare project (Access to Timely Formal Care, htttp://www.actifcare.eu/) (Kerpershoek et al., 2016), a three-year long EU Joint Neurodegenerative Programme Disease Research (JPND) project. The participating countries were Germany, Ireland, Italy, The Netherlands, Norway, Portugal, Sweden and United Kingdom. The overall objective of Actifcare was to generate best practice recommendations regarding access to formal dementia care services that can be integrated into European health and social care systems.

Objective

The objective of the present study was to map interventions used to improve access and use of formal community care services for home-dwelling people with dementia and their informal carers. The research questions were:

1. What types of interventions have been studied?
2. Which methods and outcomes are used to evaluate these interventions?
3. What results have been presented?

Methods & analysis

A preliminary literature search for studies on the effect of interventions to enhance access to care services indicated a low number of studies with a wide variation in methodologies. Consequently, the broader approach of the scoping review methodology was judged appropriate as it includes studies with different designs and grey literature. This makes it inappropriate to use critical appraisal, for instance meta-analyses, to judge the evidence. A scoping review is used to identify gaps in the evidence base, draw conclusions regarding the overall state of research activity in the area of interest, summarize and disseminate research findings. It does not include a synthesis of evidence or assess the quality of the evidence (Arksey & O'Malley, 2005).

Inclusion and exclusion criteria

The target group was home-dwelling people with dementia, or suspected dementia, and their informal carers. If a study had participants from multiple populations (e.g. people with and without dementia), data relating to people with dementia and/or their informal carers had to be presented separately for the study to be included. The outcome of the study had to be access to or utilization of formal community health and social care services as a result of an intervention. Formal community dementia care services were defined as home nursing care, day care services, in-home long-term medical nursing, social care structures and processes. The term "social care structures and processes" was used to capture differences in systems or settings across countries. The term may also include health services, as some countries define certain health services as social services. The systems of the different countries vary regarding

degree of integration, and non-private versus private structures. There are also variations in processes which open up pathways to accessing other services. In this scoping review, support from private providers like Alzheimer's Society and referral to services are included in this term.

Studies from both licensed international databases and grey literature, published from 1980 to present, could be included. Studies had to be written in English or in the languages of the participating countries of the Actifcare study. All types of intervention study designs were eligible for inclusion.

Studies were excluded if the population was residents in nursing homes or residential homes. Studies were also excluded if the outcomes did not include access or use of community care services. Studies concerning specialist medical health care and medication were excluded. As were; book reviews, opinion articles, commentaries, letters or editorials, interviews, lectures, legal cases, newspaper articles and patient education handouts.

Search strategy

Licensed international databases

Databases searched were Medline, PubMed, PsycINFO, CINAHL. Meta-databases searched were Cochrane Database of Systematic Reviews and Social Science Citation index. Two librarians at the Norwegian National Advisory Unit on Ageing and Health conducted the search with input from the Norwegian research team, in consultation with experts at the Norwegian Knowledge Centre. A combination of Medical Subject Heading [MeSH] terms and free text terms was used in the search string: "Dementia [Mesh] AND ((access* OR utilization OR "use" OR "nonuse") adj5 (care OR healthcare OR formal OR service)).ti,ab." A narrow operator search filter, N5, was applied. N5 means that there can only be five or less words between the search terms. The N5 was used to specify the association between "access", "use" and "service" and avoid citations where "access" was used in other settings,

for example in connection with cell biology. Two searches applying N5 were performed; one with a filter for quantitative study designs and one with a filter for qualitative designs. It was not possible to apply such filters in the Cochrane Database of Systematic Reviews and The Social Science Citation Index. The Social Science Citation Index and hand search of reference lists were used for backward and forward citation checking of all selected papers. The search results were uploaded into an EndNote bibliographic software file. Experts of the Actifcare consortium were asked to check for omissions of relevant studies.

Grey literature

Grey literature was searched using the same search terms and inclusion criteria as in the search in licensed international databases. Ten sources of international grey literature (textbox 1) were searched by the Norwegian research team. The Actifcare partners in each country searched national databases found relevant based on the inclusion criteria. The results were translated into English using a predefined template (type of document, intervention, aims, study population, methods, limitations, duration, outcomes and results, reference) and reported to the Norwegian research team.

Selection of studies

A template (population dementia, community care, access/use, intervention) was developed based on the inclusion and exclusion criteria and used to screen the search results. A pilot search was conducted to refine the template in October 2015. Two reviewers from the Norwegian research team (JR, MM) independently screened 150 titles and abstracts from Medline. The lists of studies included and excluded by the two reviewers were compared. Both reviewers included four papers of which three were identical. Both reviewers included the other's fourth paper on the "unsure-list". The level of agreement was assessed as good.

Licensed international databases

The search was conducted in November 2015 and updated in February 2018. One of the reviewing authors from the Norwegian research team (JR) screened the titles and excluded medical/medication studies and studies focusing on nursing home populations. The two Norwegian reviewing authors (JR, MM) screened the abstracts of the remaining studies independently. Based on screening of abstracts, full texts were obtained for papers that appeared to meet the inclusion criteria, or where the reviewers needed more information to judge. The two reviewers (JR, MM) independently examined the full texts of the selected studies. The lists of included studies were compared and disagreements regarding inclusion were resolved in consultation with a senior researcher (GS).

Grey literature

The search in international sources was conducted in March 2016. The Norwegian research team screened the resulting pages of hits, ranked by relevance, until the hits became irrelevant. The Norwegian research team screened the results of the searches in national databases conducted by the eight Actifcare partners from October to December 2015.

Please insert Textbox 1. Sources of international grey literature here

Charting of data

Data from the included publications were extracted and summarized by one of the reviewing authors and checked for accuracy by the second in order to reduce bias and errors (Arksey & O'Malley, 2005). The extracted data included type of document, study design, sample, duration, description of the part of the intervention that had access or use of services as outcome, outcome measures regarding access or use of services, and reported results regarding access or use. To organize the findings, interventions were categorized according to the measures used to enhance access or utilization. The categorization of the interventions

was piloted by one of the two Norwegian reviewing authors (JR) and discussed with the other (MM) before the final categorisation was resolved. For each outcome, the reported result was described as a positive effect or no effect/negative effect on access and use of care services (table 1).

Results

A total of 3029 papers were retrieved from the first search. After duplicates were removed, 2828 papers remained, and 105 of these underwent full text screening. Ten papers met the inclusion criteria, and five papers were included from other sources. The search was updated in February 2018. In the updated search, a total of 442 citations were screened, 14 papers underwent full text screening. One study was included from this search (figure 1). In total, 16 papers were analyzed (textbox 2).

Please insert Figure 1 Flow chart of selection of studies here

Study setting and design

Ten of the 16 included publications were from the United States, four from Germany, one from The Netherlands and one from Canada. Very few publications from low- or middle-income countries were identified, none met the inclusion criteria. Thirteen publications were peer-reviewed journal articles. Two German publications were project reports not published in a scientific journal, these were based on the same study.

Seven publications were randomized controlled trials (Amjad et al., 2018; Donath et al., 2010; Lawton et al., 1989; McCallion et al., 2004; Newcomer et al., 1999; Vickrey et al., 2006; Weinberger et al., 1993). Three were non-randomized controlled trials (Ament et al., 2015; Bass et al., 2013; Romero et al., 2007). Six publications were one-group pretest – posttest

trials (Aranda et al., 2003; Emme von der Ahe et al., 2011; Emme von der Ahe et al., 2010; Lathren et al., 2013; Lee et al., 2014; Tompkins & Bell, 2009).

The target groups of the interventions were people with dementia (1 study), informal carers (5 studies), dyads (person with dementia and their informal carers) (7 studies) or health care personnel/ general practitioners (GPs) (3 studies).

The sample sizes of intervention groups varied from 29 (GPs) to 2682 (dyads), the total number of participants of intervention groups was 5941 with a mean of 371. Follow-up varied from four weeks to four years. The papers were published between 1989 and 2018, six were published after year 2010. Textbox 2 presents sample, follow-up, design, descriptions of the interventions, relevant outcome measures and reported results.

Types of outcomes

Only two studies had access or use of services as the primary outcome (Lawton et al., 1989, Weinberger et al., 1993), most of the studies had more than one outcome. Nine studies had use of a form of day care as an outcome, 13 studies had use of some sort of respite care as one of the outcomes. All types of respite were categorized as day care services in this study. Different terms were used for the day care services. As they were not described in detail, it is difficult to know the difference between them. The terms used in the respective articles have therefore been used for these services, for instance “companion”, and “live-in help”. Other outcomes were use of home care/personal care/community care (categorized as home nursing care), home nursing (categorized as in-home long-term medical nursing), referral to different types of services and Alzheimer’s Society services (categorized as social care structures and processes) (table 1).

Types of interventions

Five types of interventions were identified; Case management, Monetary support, Referral enhancing, Awareness & information focused and Inpatient focused (see textbox 2 and table 1). Referral enhancing interventions were included as a category because referral was perceived to provide potential access. Potential access is the presence of enabling resources, allowing the individual to seek care if needed (Andersen, 1995).

Please insert textbox 2 here.

Effects of the various interventions

Fourteen studies, representing all five types of interventions, had positive effects on one or more relevant outcomes. However, one case management intervention had a positive effect on use of in-home respite and home care but no effect on use of day care (Vickrey et al., 2006). Two of the studies had no effect on relevant outcomes; one was a referral-focused intervention (Ament et al., 2015), the other used monetary support in combination with case management (Lawton et al., 1989) (table 1).

Please insert table 1 here

Referral enhancing interventions

Three studies used referral as a means of choice to enhance access to community services. Two studies used training programs for physicians focusing on information about service providers and referral to services. One of these two reported 160 physician-initiated referrals to caregiver respite services including adult day care two years following the intervention, compared to almost never receiving referrals before the intervention (Lathren et al., 2013). The other found a fivefold increase in referrals to the Alzheimer's Society, which could provide home care, adult day programs and respite, in the 6 months following the intervention

(Lee et al., 2014). A third study used a geriatric nurse practitioner as a link between a multidisciplinary community mental health team and the general practitioner to enhance concordance with advice from the multidisciplinary team regarding referral to services. Rates did not differ between the intervention and reference group with respect to day care or home care referrals (Ament et al., 2015). In sum, two of the three studies in this category reported positive effect on referrals to relevant services. The studies were from the Netherlands, USA and Canada. There was no randomized controlled study (RCT) in this category.

Awareness and information focused interventions

Two studies used information to the public about dementia and available services to raise awareness (Aranda et al., 2003; McCallion et al., 2004). One used different types of media, such as bilingual helplines, electronic media advertising and community fairs to provide information about dementia and services to the Latino ethnic minority. This study found positive results for use of adult day care and use of in-home respite compared to pretest (Aranda et al., 2003). The other targeted carers in general and referred people to an Alzheimer Association chapter for information about suitable community services. They reported a greater increase in use of respite and day care for the intervention group compared to the waiting list group (McCallion et al., 2004). Both studies in this category reported positive results for all relevant outcomes. Both studies were from USA. One study was an RCT.

Case management interventions

Seven papers used some sort of case management intervention. The interventions encompassed assessment of needs, information and recommendation of available services, often set up in an individualized service plan, as well as the health care professional's application of electronic care coordination software. One study found that change in use of

services like social day care, companion services and in-home respite care, was significantly different between groups with a greater increase in use among participants in the intervention group (Amjad et al., 2018). Another reported that while higher proportions of participants in the intervention group received respite care than in the usual care group, there was no difference in the use of day care (Vickrey et al., 2006). A third found that the carers in the intervention group had a significant increase in likelihood of using respite from baseline to 6 months compared to the control group (Bass et al., 2013). One study reported positive results for use of home nursing, day care, and institutional short-term nursing at follow up compared to the usual care group (Donath et al., 2010). Emme von der Ahe and colleges (2010) found increase in number of families that used short term care and respite care from baseline to follow-up (Emme von der Ahe et al., 2010). This study had a follow-up study targeting people with dementia in early stages which reported increased utilization of all of the services compared to baseline (Emme von der Ahe et al., 2011). Weinberger and colleges reported no effect on day care and respite (referred to as "companion", and "live-in help") (Weinberger et al., 1993). In sum, six of the seven papers in this category reported positive results for one or more outcomes. Four studies were from USA, three were from Germany. Three studies were RCTs.

Monetary support interventions

Three studies tested monetary support to buy services, like a voucher-type respite grant, case management in combination with monthly limited service reimbursement provided by the project, or monthly community care benefits. In the first study, the treatment group was at least twice as likely to be using home care (including personal care services) and adult day care, compared to the control group (Newcomer et al., 1999). In the second study, there was a higher increase in use of help in the home, day program and short stay at a nursing home at

the 6-month follow-up for the group that received a voucher grant and the group that received this in combination with psychoeducational training, compared to the group which received only psychoeducational training (Tompkins & Bell, 2009). The third study reported that the experimental and control subjects were equal in using slightly more services (Lawton et al., 1989). Two of the three studies in this category reported positive results for one or more outcomes. All three studies were from USA. Two studies were RCTs.

Inpatient focused intervention

A study aimed to prepare patients admitted to an institution and their families for life at home by enabling them to use community support services (Romero et al., 2007). They reported a significant positive effect on the outcome, which was use of day care, at follow-up compared to the waiting list group. This study was from Germany. It was a non-randomized controlled study.

Discussion

This scoping review identified five types of interventions. Referrals was used as an enabling resource for access to services in the category *"Referral enhancing interventions"*. It is, however, unclear whether the referrals resulted in better access to and use of the services people with dementia and their informal carers were referred to. The interventions in *"Awareness and information focused interventions"* targeted the population's lack of information about dementia and available services. This barrier is well documented (Mukadam et al., 2013), but the present scoping review indicates that the amount of research regarding interventions to overcome it does not match its documented extent and significance. The positive results in the category *"Monetary support interventions"* are in line with the

finding from the Actifcare project regarding socioeconomic aspects of access to formal dementia care services. This study indicated that private out-of-pocket payments could contribute to lower service utilization (Bieber, Broda, & Stephan, 2014; Bieber et al., 2017). When user fees represent a barrier for potential service users, monetary support seems to be a means that can help them overcome this hindrance. The category "Inpatient focused intervention" showed that a hospital stay represents an opportunity to promote use of relevant community services that should not be overlooked.

"Case management interventions" was the largest category. Two interventions in the category "*Monetary support*" also used case management, in combination with monetary support. The number of studies makes the evidence for an effect more solid for case management than for the other types of interventions. Care systems often fall short of excellence in response to the complex biopsychosocial needs of people with dementia. Concerns about expertise and referral resources have been raised that call for structural changes of care provision (Boustani, Sachs, & Callahan, 2007; Harris, Chodosh, Vassar, Vickrey, & Shapiro, 2009; Hinton et al., 2007). This has led to a focus on models of care that align with case management (Longworth, 2011). Case management has emerged as a viable approach for alleviating fragmentation of care. Studies have found that case management may reduce unmet needs and improve self-reported quality of life and quality of care (Callahan et al., 2006; Samus et al., 2014; Vickrey et al., 2006). The Cochrane review of Reilly et al., (2015) did not find enough evidence to clearly assess whether case management could delay institutionalisation in care homes. Some studies indicated that case management was more effective than non-case management interventions at reducing carer burden and depression and improving carer well-being at six months and social support at 12 months (Reilly et al., 2015).

There is, however, not a set definition of case management, different terms are used for this type of function, for instance care management and care coordination. There is great variation in how case management is organized and implemented, and long-term care funding policies and cultural variations in different countries influence access to this type of care (Reilly et al., 2015). However, a main feature is a key contact person who oversees and coordinates care delivery (Verkade et al., 2010; McDonald, Sundaram, & Bravata, 2007). The need for such a key contact person to enhance access was the key finding of the Actifcare project. The need for a coordinating role was one of the major findings in the expert interviews with policy and political decision makers, or representatives of relevant institutions in the eight Actifcare countries, to determine their perspectives on access to formal care for people with dementia and their carers (Broda et al., 2017). It was also a central finding in the focus groups conducted in the Actifcare project which focused on the experiences of access to services of people with dementia, their informal carers and health care professionals (Stephan et al., 2015, Stephan et al., 2016, Stephan et.al.2018). The significance of a key contact person was reaffirmed in the Actifcare Delphi process used to develop the Actifcare Best Practice Recommendations to enhance access and use of formal community care services (Røsvik et al., manuscript in preparation). The Actifcare Delphi process included 34 people with dementia and their informal carers in addition to 42 professional experts, and reached consensus on these recommendations regarding the contact person's tasks: The contact person should proactively establish and maintain contact with the person with dementia and informal carer, preferably immediately after the diagnosis, provide personalized information about dementia and services, regularly assess the needs of the person with dementia and carer, including psychosocial needs, and provide support in decisional conflicts between the person with dementia and carer (The Actifcare Best Practice Recommendations, www.actifcare.eu). This description of the tasks and responsibilities of the key contact person corresponds well

with the foci of other categories of interventions described in this review, for instance facilitation of referrals to services and provision of information about dementia and formal community services.

Most of the studies had use of different forms of respite and day care as outcomes. Home care nursing, which may be seen as the classical type of formal community service, was rarely focused on. We do not know the reason for this. It may be that conceding that one needs help to function at home and accept help from strangers takes longer time, which makes this type of service less suited to measure as an outcome in a research project with a short time frame.

Seven of the 16 included studies used an RCT to evaluate the effect of the intervention. The rest of the studies, constituting the majority of the studies, used designs that limited the generalizability of the results to a larger population and where conclusions about causality were less definitive. It is difficult to gauge how much the characteristics of the national systems, which the interventions included in this review were tailored to, affect the generalization of the results to other countries with other systems. Differences in health care systems and culture may impact the effectiveness of the interventions.

Limitations and strengths

A systematic assessment of the quality of the included studies in this review was not performed, and it should be noted that some of the studies were non-peer reviewed project reports. Scoping reviews can incorporate a range of study designs in both published and grey literature, address questions beyond those related to intervention effectiveness, and generate findings that can complement the findings of clinical trials (Levac, Colquhoun, & O'Brien, 2010; Arksey & O'Malley, 2005; Hasson, Keeney, & McKenna, 2000; Keeney, Hasson, & McKenna, 2006). Scoping reviews are particularly relevant to disciplines with emerging evidence and fewer studies with robust designs, which was the situation here. The inclusion of

grey literature provided a wider scope of the field. Searches for grey literature were conducted in both international sources and national sources of the Actifcare countries. The search strategy used was guided by systematic review methodology, and extensive and lateral searches of databases were employed.

Conclusion

Fourteen of the 16 intervention studies included in this scoping review reported positive effects on one or more relevant outcomes. Five categories of interventions were described. The number of studies makes the evidence for an effect more solid for case management than for the other types of interventions. Because of heterogeneous interventions and outcomes as well as few studies with high quality design in some of the categories, these results do not represent a robust evidence base. This scoping review found that few interventions to enhance access have been systematically evaluated. Access to appropriate formal care for people with dementia and their informal carers should be a priority for health care systems, therefore, more studies using robust research designs in the testing of interventions in this field are recommended.

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Textbox 1. Sources of international grey literature

Open grey System for Information on Grey Literature in Europe.	http://www.opengrey.eu
Grey literature report. A bimonthly publication of The New York Academy of Medicine alerting readers to new grey literature publications in health services research and selected public health topics.	http://www.greylit.org/
OAlster. Combined bibliographic catalogue of open access material	http://oaister.worldcat.org/search
World Health Organization	http://apps.who.int/trialsearch/
OpenDOAR. A service based on the Google Custom Search engine. Gives access to freely available academic research information.	http://www.opendoar.org/
Mednar. Search engine designed for professional medical researchers	http://mednar.com/mednar/desktop/en/green/results.html
ProQuest. Search engine that powers research in academic, corporate, government, public and school libraries around the world	http://www.proquest.com/
Google Scholar	http://scholar.google.no/scholar
Alzheimer-Europe	http://www.alzheimer-europe.org/
The Health Technology Assessment (HTA) Programme Database	http://www.inahta.org/hta-tools-resources/database/

Textbox 2. Types of interventions. Summary of design, relevant outcome measures and results of included studies

Referral enhancing interventions				
Reference Year Country Type of document	**Relevant part of intervention**	**Design Sample Control Follow-up**	**Relevant Outcome measures**	**Relevant results**
Ament et al 2015 Netherland Journal article	A care coordinator (geriatric nurse practitioner) was used to communicate the advice regarding treatment and management from a multidisciplinary community mental health team to the general practitioner (GP)	Design: Non- randomized controlled study Sample:114 persons with dementia Control: historical reference sample of 137 persons with dementia Follow-up:12 months	GPs' concordance with care service recommendations from a multidisciplinary team regarding referral to home care and daycare center	Concordance rates did not differ between the two cohorts
Lathren et al 2013 USA Journal article	One-day training program on dementia screening, diagnosis and management that included direct engagement with local support service providers	Design: one-group pretest - posttest study Sample: 29 physicians and 24 affiliated staff Follow-up: 6 months	Frequency of referrals to community resources that offers funding for caregiver respite services including adult day care	160 physician-initiated referrals were received the two years following the intervention compared to almost never receiving referrals before the intervention
Lee et al 2014 Canada Journal article	Nurses, social workers and gerontologists from the Alzheimer's Society (AS) took part in the assessment and management of patients in the memory clinics to help linking patients and families to community services.	Design: one-group pretest–posttest study with quantitative and qualitative data Sample: survey: 35 memory clinic healthcare provider, 9 AS representatives, focus groups: 25 memory clinic members, 11 AS representatives Follow-up: 6 months	Frequency of referrals from memory clinics to the AS which offered home care, adult day programs and respite. Impact on access to information and community supports at the time of diagnosis, healthcare providers' awareness of available community services	A fivefold increase in referrals to the AS in the 6 months following the launch of the partnership (mean: 4.7; SD 0.54). Respondents (>84%) indicated positive impacts for patients and caregivers regarding access to respite. Interview participants identified increased awareness of and timely access to AS programs such as home care, adult day programs and respite
Awareness and information focused interventions				
Aranda et al 2003 USA Journal article	Culturally specific outreach and delivery strategies were used to improve public awareness and provide information about ethnic sensitive dementia and services available to the general Latino public: Bilingual helplines, electronic media advertising and community fairs	Design: One-group pretest posttest Sample:273 informal caregivers. Follow-up: 4 years	Use of adult day care, in-home respite	Percentage of unduplicated service use per household as a result of the project: 36% for adult day care, 33% for in-home respite compared to no use at pretest

McCallion et al 2004 USA Journal article	Information and referral to an Alzheimer Association chapter to get help to finding needed community services. The control group was assigned to a waiting list	Design: RCT Sample: 203 informal caregivers were randomly assigned to treatment and waiting list control conditions Follow-up: 6 weeks	Use of in-home respite and adult care, out-of-home respite	A significantly greater increase in use of respite and day care for the intervention group compared to the waiting list group
Case management interventions				
Vickrey et al 2000 USA Journal article	Health care organization- and community agency based dementia care managers (mainly social workers) received formal training and used an internet-based care management software system for care planning and coordination. Intervention participants received structured home-assessment including care plan actions sent to the primary care physician, reassessments every 6 months in the home as well as follow-up by phone. The control group received usual care	Design: Clinic-level, cluster randomized, controlled trial Sample: 9 clinics, 238 dyads Control: 9 clinics, 170 dyads Follow-up: 18 months	Receipt of services: information, respite care, home health aide services, and professional caregiver services, e.g. use of adult day care	Significantly higher proportions of participants in the intervention group than in the usual care group received services or information from 1 or more community agencies and received respite care and professional caregiver services. 27.3% of participants in the intervention group compared with 8.4% of participants in the usual care group were enrolled in an Alzheimer's Association program. Use of adult day care did not differ.
Bass et al 2013 USA Journal article	One care coordinator from a Veteran Affairs health organization and one from Alzheimer's Association worked as a team and shared an electronic care coordination system. The participants got an initial assessment, an action plan and ongoing monitoring and reassessment. The control group had access to the services they were entitled to as usual	Design: Non-randomized controlled study Sample: 228 carers/dyads Control: 187 Follow-up:12 months	Use of respite	The intervention caregivers had 61.3% increase in likelihood of using a caregiver respite service from baseline to 6 months, a significant difference in change at 6 months compared to the control group. The improvements at 12 months were more limited.
Weinberger et al 1993 USA Journal article	A social worker made extensive contacts with local service agencies to assess services offered and families' eligibility for services and developed individualized service plan. The control group received a general information packet with written information about AD	Design: RCT. Sample:193 informal carers Control: 71 informal carers Follow-up:6 months	Use of adult day care, sitter/companion and live-in help	No effect of the intervention on adult day care, sitter/companion and "live-in help"
Donath et al 2010 Germany Journal article	Study with three arms. Arm A constituted usual care, in Arm B and C support groups and caregiver counseling were recommended by the general practitioners (in Arm B one year after baseline, in Arm C at baseline). The general practitioners received arm-specific training	Design: prospective, three-arm cluster-randomized 2-year study Sample:303 general practitioners were randomized. Of these, 129 practitioners enrolled 390 patients in the study, 357 informal caregivers of these patients were questioned	Use of home nursing, daycare, institutional short-term nursing	Group-independent significant changes in utilization over time during the two years in the sense of increased utilization were observed for home nursing, institutional short-term nursing and daycare, but this increase was group-specifically significant only for home nursing (in all three arms) and institutional short-term nursing (in Arms A and B).

		Control: usual care Follow-up: 2 years		
Emme von der Ahe et al 2010 Germany Project report	Individual targeted support program with proactive care and continued guidance. Overall support concept for people with dementia designed to provide general relief to caregivers	Design: One-group pretest - posttest. Sample: 319 families Follow-up: 18 months	Use of short term care, respite care and transformation of short term care into respite care	Before the project, 58% of the families did not use short term care and respite care. During the support program, 94% used at least one service, 53% used all three, 28% used two, 13% used one.
Emme von der Ahe et al 2011 Germany Project report	Follow-up project of von der Ahe et al 2010 that adjusted the model to fit the needs of people with dementia in early stages. This study used both qualitative and quantitative methods	Design: One-group pretest-posttest. Sample: 104 families Follow-up:18 months	Use of short term care, respite care and transformation of short term	Increased use of home care with ADL of 3.8%, day care by 34.6%, short term care with 12.5%.
Amjad et al 2018 USA Journal article	Care coordination through an interdisciplinary team of nonclinical memory care coordinators linked to a RN and a geriatric psychiatrist. Provision of individualized care planning based on unmet needs, dementia skill building, referrals and counselling	Design: RCT Sample: 110 people with dementia > 70 years old and their partner Control: 193 received usual care Follow-up: 18 months	Social support: Social day care, companion services, in-home respite care, congregate meals	Change in social support was different between groups with greater increase in use among interventions participants. While the mean types of social support use were non-significantly higher in the intervention group at 18 months (p=.087), the rate of increase was significantly higher in the intervention group (p=.026)
Monetary support interventions				
Lawton et al 1989 USA Journal article	Case management offering three types of respite: 1:in-home respite (a sitter), 2: adult day care, 3: institutional respite care. The project could contact the respite care, provide the requisite information to the caregiver and help pay the cost. A family could have any mix of formal and informal resources for respite or none at all, and no help, partly or full help to pay the cost. The control group was not offered respite	Design: RCT Sample:316 volunteer caregivers Control: 315 volunteer caregivers not offered respite Follow-up:12 months	Prevalence of different forms of respite services used.	The experimental and control subjects were equal in using slightly more services.
Newcomer & Spitalny 1999 USA Journal article	Two case management models were implemented. These differed by case manager-to-client ratios and service expenditure ceilings per month for each client. Model A sites operated with a target case manager-to-client ratio of 1:100 and had a monthly community service reimbursement limit of $290 through $489 per month per client Model B sites had a target case manager-to-client ratio of 1:30 and a slightly higher reimbursement limit of $430 through $699 per month per client. Per month reimbursement caps in each model varied by site over time due to regional cost variations and inflation adjustments	Design: RCT. Sample: 2682 dyads Control: 2527 dyads received usual care Follow-up: 12 months	Home care and adult day care (including personal care services, companion services)	A strong, consistent, and positive effect on the likelihood of using home care (including personal care services, companion services) and adult day care. Treatment group were at least twice as likely to be using any of the four community-based services. Within the limits of the monthly payments and the case manager-to-client staffing ratios, there was no systematic advantage for the high-resource model over the lower-resource model when they are examined across the four sites in each model.

	The control group received usual care			
Tompkins et al 2009 USA Journal article	3 interventions: 1.provide psychoeducational training for informal caregivers, create reliable and accessible networks of support, increase access to supportive services (SCP) 2.a voucher-type respite grant for up to $1,000 per family through the Alzheimer's Association as reimbursement for use of adult daycare, in-home care, or other respite services (Grant) 3. combination of 1 and 2 (Both)	Design: Pretest-posttest SCP: 127 informal caregivers Grant: 197 informal caregivers Both: 43 informal caregivers Follow-up : 6 months	Support service use: help in the home, day program, short stay at a nursing home.	A significant increase in use of support types of service at 6-month follow-up for all treatment groups. The Grant and Both groups showed a higher, but not significant, increase in support service usage compared to the SCP group
Inpatient focused intervention				
Romero et al 2007 Germany Journal article	A multimodal inpatient rehabilitation program established as a clinical service to prepare families for life at home and enable families to use wider social supports and non-medical treatments	Design: Non-randomized controlled study Sample: 35 dyads Control: waiting list group Follow-up: 4 weeks	Use of day care	Use of day care increased from pretest 20% to follow-up-test 42.4% within the treatment group, and non-significantly increased from pretest 7.7% to follow-up-test 16.7% within the waiting list group.

Table 1. Outcomes and effect of the included studies for the five types of interventions

Type of intervention **Outcome**	**Referral enhancing interventions** *3 studies*		**Awareness and information focused** *2 studies*		**Case management focused interventions** *7 studies*		**Monetary support interventions** *3 studies*		**Inpatient focused intervention** 1 study	
	Positive effect	Negative/ no effect	Positive effect	Negative/ no effect	Positive effect	Negative/ no effect	Positive effect	Negative/ no effect	Positive effect	Negative/ no effect
Social care structures and processes										
Referral to day care		Ament 2015								
Referral to respite	Lathren (a) 2013									
Referral to home care/ community care*		Ament 2015								
Referral to Alzheimer's Society services	Lee (c) 2014									
Day care services										
Use of day care			Aranda 2003 McCallion 2004		Donath 2010 Amjad 2018	Vickrey 2000 Weinberger 1993	Newcomer 1999 Tompkins 2009		Romero 2007	
Use of respite/out of home	Lee (c) 2014		McCallion 2004				Tompkins 2009			
Use of respite/ in-home/ sitter			Aranda 2003		Vickrey 2000 Amjad 2018	Weinberger 1993		Lawton (d) 1989		

companion/ live-in help			McCallion 2004				Newcomer 1999			
Use of respite incl. emotional support					Bass 2013					
Use of respite/ short term care					Emme von der Ahe(b) 2010/2011 Donath 2010					
Home nursing care										
Use of home care/ personal care/ community care*					Vickrey 2000	Weinberger 1993	Newcomer 1999			
In-home long-term medical nursing										
Use of home nursing					Donath 2010					

*Service not specified/described/differentiated

a= no p-value given, but increase in referrals from "almost never" or "did not recall ever" to 60 – 100 new referrals

b= no p-value given, but use of at least one of these services has risen from 42 % to 94%

c= no p-value given, percentage increase in referrals: 100% to 1067%

d= the experimental group had a significant higher service use in the multivariate test compared to the control group, but the absolute amount of increase was relatively small

Figure 1 Flow chart for selection of studies