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Improving health-promoting self-care in family carers of people with dementia: A review of interventions

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Abstract

Background: Providing care for a family member with dementia can leave little time for carers to look after their own health needs, which makes them more susceptible to mental and physical health problems. This scoping review aimed to explore potential health benefits of interventions aimed at improving health-promoting self-care in family carers of people with dementia.

Methods: A scoping review was carried out using Arksey and O'Malley's methodological framework. EMBASE, MEDLINE, PsycINFO, Google Scholar databases. Original and peer-reviewed research published in English up to April 2017 were included. Publications were selected by two reviewers independently. Eight experts from several countries provided extra relevant information, which was triangulated with the review results. A narrative approach was used to describe and discuss the review findings.

Results: Seven interventions were identified. These were highly heterogeneous in content, method of delivery and outcome measures. None was specifically focused on improving and evaluating health-promoting self-care, instead they often focused on health promotion and healthy lifestyle (e.g. physical activity). Some of the multi-component interventions included 'self-care' as a domain, but as none used a specific measure of health-promoting self-care, so we are unable to affirm that the improvements found in the interventions were due to an improvement in this area. Interventions helped reduce carer depression and burden and increased quality of life, positive affect and physical activity. The expert panel recommended to consider carers' preparedness and capacity to adhere to self-care practices, as well as carers' age and culture. Future interventions should be context specific, flexible and person-centered.

Conclusions: Psychosocial interventions may improve health-promoting self-care behavior, but more research is needed to establish efficacy. Interventions should be

flexible, use a person-centered approach, be implemented with fidelity and use the right dosage.

Keywords: Alzheimer's disease; Dementia; Carers; Health promotion; Scoping review; Self-care

Running header: Health-promoting self-care in family carers

Introduction

Caring for a family member with dementia can have negative consequences for the physical and mental health of family carers due to the high levels of burden, stress and loneliness often resulting from this role.[1,2] Carers can be reluctant or unable to seek help for health issues due to intense caring routines and psychological difficulties, such as guilt,[1,3] which may lead to a higher number of illnesses and higher mortality rates, as well increased hospital admissions and care-home placement for the person cared for.[4,5] Understanding how family carers can care for their own health better may potentially contribute to a reduction on the negative health and well-being effects of caring for someone with dementia.[6-8]

Health-promoting self-care comprises the actions taken by individuals to improve their health, maintain good functioning and increase well-being, in response to illness or simply to promote health.[9,10] This enables services to support people to identify and develop their own strengths and abilities to meet their needs, according to their own capabilities and preferences.[10] Improving self-care behavior is relevant not only for preventing health issues, but also in mediating the course of long-term conditions.[11] This has the potential to empower individuals with chronic conditions to better look after their own health, helping inform day-to-day decisions and management of illnesses and

health,[12-16] improving adherence to treatment, quality of life, patients' knowledge of their illness and self-management.[17] In doing that, care programmes can be optimised as individuals are encouraged to depend less on services to have a healthy life, which in turn may reduce service costs.[18]

Health-promoting self-care is a key strategic area within national and international health policies and we need to know how to promote this for carers.[19] Health-promoting self-care can be considered an outcome on its own right as it reflects people's overall ability to care for their own health and wellbeing and may have impact across lifespan. However, it may also function as a mediating variable in the sense that individuals' health and wellbeing could be improved through the increase on the levels of health-promoting self-care. Much of the health-related research on family carers is about the negative experiences or problems arising from the caregiving role and is based on stress-coping frameworks.[9] There is limited evidence on the approaches to health-promoting self-care in family carers of people with dementia and its potential benefits to carers' health and well-being. Therefore, this scoping review aimed to explore the potential benefits of interventions aimed at improving health-promoting behavior, which could potentially be implemented in public health services to help family carers look after their own health better.

Material and Methods

A scoping review method was adopted as it was aimed to explore more broadly the potential benefits and research gaps to inform a future systematic review on this topic.[20] A transparent approach to data selection, collection and analysis was used to produce a broad map of the literature.[21] A scoping review framework[22,23] was used to ensure the quality and robustness of the review, in line with Cochrane recommendations.[21] This framework has six sequential steps: i) identifying the

research questions; (ii) identifying relevant studies; (iii) study selection; (iv) charting the data; (v) collating, summarizing and reporting the results; and (vi) expert consultation.

Search strategy

This literature search was guided by the following research question: What are the benefits of health promoting self-care attitudes, behavior, approaches and interventions most commonly used by or with family carers of people with dementia?

The following keywords was used for the literature search: (dementia OR Alzheimer's disease) AND (caregivers OR carers OR informal care OR non-professional care OR non-formal care OR family care OR unpaid care) AND (health OR health status OR mental health OR physical health OR health care need OR health need OR health issue OR health problem OR unmet need OR health literacy OR health behavior OR health behaviour OR health belief model OR health belief OR attitude to health OR health attitude OR self-management or self management OR self-care OR self-efficacy OR self-regulation OR autoregulation OR self-care agency OR self-care agency).

EMBASE, MEDLINE, PsycINFO and Google Scholar databases were used to identify relevant studies. The search strategy was adapted to the requirements of each database, using appropriate Boolean operators and coding to increase search sensitivity. The references of included papers were also checked for any relevant information.

Inclusion criteria

All papers published prior to the search date (April 2017) were considered. Only original and peer-reviewed research published in English were included. No inclusion/exclusion criterion for study design or specific methodology was used so as to

increase the search sensitivity. Studies containing the following characteristics were included (PICO framework):

- Individuals providing unpaid care for family members living with dementia (Population).
- Interventions including health promoting self-care strategies/models (Intervention/Experience).
- General population, carers receiving treatment as usual or placebo, other disease groups, or no control (Control).
- Health-promoting self-care (either as an outcome measure or mediating variable), health behavior, physical and mental health-related outcomes (Outcomes/Variables).

Exclusion criteria

Editorials, opinion papers, dissertations and conference abstracts were not included. Publications focused on carer-management of the dementia symptoms, methodological papers on adherence to interventions, service use or help-seeking behavior were excluded. Articles that did not report any intervention were excluded.

Search outcome

First, titles and abstracts were reviewed (Figure 1). Relevant articles were read in full and selected by two reviewers independently (DO/LS). A third reviewer (MO) was consulted in cases of disagreement between the two reviewers regarding study inclusion. Quality appraisal is not usually carried out in scoping reviews as the amount of data included is normally large and data synthesis is minimal.[21] Therefore, all the eligible papers were submitted to data extraction (n=7) according to the guiding review question.

Expert consultation

As per required by the scoping review framework adopted,[21] an expert consultation was also undertaken. Fifteen research experts in the fields of family carers' health and self-care were identified including via the papers found in the literature search. These were invited to complete an online questionnaire containing 11 open questions regarding the following topics: relevance of this field of research; current approaches to health promoting self-care and self-management in carers; gaps, limitations, strengths and future directions in in the field. A total of eight clinical and academic experts in dementia caregiving returned completed questionnaires, including seven Professors. These were research psychologists (n=5) and nurses (n=3) by background, from the UK, the Netherlands, USA, Finland and Sweden. One was from World Health Organization and another from the Eurocarers organization.

<Insert Figure 1 here>

Data extraction and synthesis

After being read several times, the included papers (n=7) had their aims, sample characteristics, study design, intervention characteristics, outcome measures and key results extracted. The information collected via the questionnaires sent to the experts was collated and discussed between the research team. The findings were compared with the articles identified in the literature search. A narrative approach was used to discuss the scoping review results and the expert comments aiming to situate the review findings within the broader research and practice contexts.[23]

Results

This scoping review included seven interventions aimed at improving health-promoting self-care in family carers of people with dementia (Table 1). Six of them were delivered via telephone or combined face-to-face with telephone-based activities, and one was online. Interventions were focused on managing dementia behavior,[24] promoting physical activity,[25,26] or combined several activities to improve various outcomes, such as social support, psychological skills and lifestyle.[27-29] Six interventions were undertaken in the United States and one in Turkey. Four were randomized controlled trials (RCTs) and three were pilot or feasibility studies. Sample sizes varied from n=137 to n=632 individuals in the RCTs and from n=6 to n=100 individuals in the feasibility/pilot studies.

None of the studies was specifically focused on improving and measuring health-promoting self-care. These were rather focused on areas that might be associated to health promotion and healthy behavior, such as physical exercise and psychological wellbeing. Some of the multi-component interventions used 'awareness of self-care practices' or 'person-centered self-care strategies',[28] or simply 'self-care',[26,29,30] to refer to health-promoting self-care practices. In addition, none of the studies used a specific measure of health-promoting self-care to identify improvements in this area. Rather, these used more generic outcome measures, such as depression, burden, and quality of life.

Randomized controlled trials

A telephone-based intervention to increase physical activity in women caring for their spouses with dementia (n=137) showed greater improvement in total exercise in the intervention group ($p<0.01$) when compared with the control group.[25] Although exercise self-efficacy improved in the post-intervention assessment when compared to baseline ($p<0.01$), there were no differences in exercise self-efficacy between control and

intervention groups. At six-months, the effect sizes were 0.15 and 0.04 for total exercise and exercise self-efficacy, respectively. Only exercise self-efficacy was significant at 12 months ($p<0.05$). This intervention used a flexible approach with individualized goals that were set by the participants in conjunction with a counsellor.

Belle et al.[30] tested the effects of a structured multicomponent intervention in a diverse ethnic group of carers (n=211). This intervention was delivered through 12-month in-home and 6 telephone-based sessions focused on a 'carer skill building programme' involving managing depression, burden, self-care, healthy behaviors, social support and dementia behaviors. The intervention increased quality of life ($p<00.1$), helped reduce depression and problem behaviors in Latinos ($p<0.001$), but no difference was found in care-home placement rates of their relatives with dementia.

Three studies (two RCTs and one pilot study) involved the same structured multicomponent intervention called 'carer skill building',[31] which includes activities for promotion of self-care and healthy behavior (e.g. a health booklet provided reminders about health maintenance activities and a tool to record health information and health appointments for both themselves and the care recipients). One RCT (n=211) tested the effects of an individualized physical activity intervention in comparison to the 'carer skill building' control group (only the module focused on managing dementia behaviors was applied).[26] The intervention showed a significant improvement in total physical activity ($p=0.01$) and decreased burden ($p=0.03$). A second study (n=295) compared the effects of the 'carer skill building' programme in relation to an information- and support-oriented control group[24] and showed that 'carer skill building' significantly improved depression levels ($p<0.05$), but no difference in efficacy was found between the two groups. These three RCTs suggested that the 'carer skill building' programme might be effective to improve carers' mental health.

Pilot and feasibility studies

Farran et al.[27] developed an online version of the 'carer skill building' programme and tested its benefits with 100 carers. Results showed a significant increase in caring skill at 6 and 12 weeks and improvements in carer depressive symptoms (p=0.01) and positive affect at six weeks (p=0.05). A feasibility study of another theory-based intervention delivered through the telephone by nurses (n=6) showed preliminary evidence of enhanced awareness of self-care practices in carers.[28] The training was focused on healthy habits, self-esteem, positive thoughts, avoiding role overload, communicating, building meaning and person-centered self-care strategies. Lok and Bademli[29] examined the effects of a self-care program on burden and healthy life style behavior in a pilot study (n=40) and found a reduction on the perceived burden and enhanced lifestyle behaviors. The programme was based on seven sessions for strengthening the carer and suggested decrease burden and promotion of healthy behaviors.

Expert consultation

Overall, experts suggested that research on family carers' health and health-promoting self-care is limited and further investigations using a broader approach to health and self-care is needed (Figure 2). Experts said that carers have more health problems than the general population because of the high caregiving demands, limited time for themselves, sleep deprivation, social isolation, poor diet, lack of ability to exercise, lack of social and emotional support, poor coping strategies, substance misuse and untreated mental and physical health problems. Services often do not consider carers' advanced age, preparedness to provide care, physical health, mental health and reluctance to accept support before carers' reach a crisis point. There is a lack of regular respite breaks, poor knowledge about the available support services in place

and a lack of national protocols in place to protect carers' health. Services should provide more information, training, support and advice. These should be more family centered, more empathetic and sensitive to carers' needs, there should be earlier identification and exposure to respite care, and there should be annual health checks and 'case managers' for every carer.

Experts recommended that research in this area should be flexible, focused on psychosocial interventions considering carers' expectations, goals, acceptance, their own needs and importance of self-care. These should be person-centered and context specific. Outcome measures to be considered are self-care; functional decline; health care utilization; self-efficacy; well-being, depression, anxiety, burden, stress, carer experience, quality of life, coping strategies, preparedness to care, satisfaction, resilience and delay in care-home placement. 'Maintenance of health' should be avoided as a parameter due to initial differences in health and the likelihood that impact on health is longer-term, rather than short-term. Researchers should a) think carefully about the intervention dosage; b) consider the carers' capacity to participate in specific self-care approaches and their readiness to change lifestyle; c) avoid 'one size fits all' approaches; d) consider different dementia caregiving stages; e) be mindful to power relationships and levels of engagement and acceptance; f) use a co-design or structured peer to peer support; g) implement interventions with fidelity; and h) involve multiple health and social sectors.

Discussion

This is the first scoping review to explore the potential benefits of health-promoting self-care interventions in family carers of people with dementia. Seven relevant studies were highly heterogeneous in content, method of delivery and outcome measures, and the vast majority was conducted in the United States. None of the studies specifically

focused on improving and measuring health-promoting self-care, but on areas that might be more broadly associated to health promotion and healthy lifestyle activities, such as physical exercise. Overall, interventions helped reduce carer depression and burden and increased quality of life, positive affect, physical activity and exercise self-efficacy. The expert panel considered this area of research important and recommend that future interventions should involve carers' preparedness and capacity to adhere to self-care practices. Carers' age and culture should be considered and a person-centered approach should be used. Important consideration also needs to be given to the fidelity of the intervention and to delivering the right dosage, so that not too much (causing a burden on carers) or not too little (low impact) of the intervention is offered.

Although the quality of the studies was not assessed as part of this scoping review, some methodological considerations can be made based on current minimum standards for psychosocial interventions.[32] For example, the high heterogeneity of the studies in terms of scope, content and outcome measures limited comparisons and would not allow for a meta-analysis to be undertaken to establish efficacy. Even though some of the multi-component interventions included 'self-care' as a domain, none of the interventions used a specific measure of health-promoting self-care to evaluate improvement in self-care behavior and its impact on carer outcomes. This might be because the first theory-based measure to assess health-promoting self-care behavior appears to have been developed only in 2018,[33] by which time only instruments to address barriers and facilitators to self-care had been developed and the studies had already been carried out. We are therefore unable to affirm whether the benefits from the interventions were due a direct effect of an increase in carers' health-related self-care behavior or due to an improvement in other outcomes (e.g. increase in knowledge, reduction in burden). Comments from expert panel indeed confirm that research in this area needs to be more robust and that the outcome measures used

need to be chosen with caution so that the importance of such health behavior for carers can be established. Although heterogeneous, the interventions showed some benefits to carer outcomes, thus future research could further explore the concept of health-promoting self-care and its use with family carers considering such findings.

Greaves and Campbell[11] noted most of the self-care research has a 'self-management approach' to specific illnesses, such as the individual capacity to manage his/her diabetes or asthma, rather than to the individual capacity to manage and maintain health and well-being more broadly. However, health-promoting self-care behavior goes beyond managing specific diseases or adhering to specific lifestyle behaviors, such as physical exercise. It involves helping individuals make better health choices and to have self-responsibility, or accountability for actions, regarding their health.[9,34] We therefore argue that, for carers to engage in health-promoting behavior, they must be motivated to take personal responsibility for their health by promoting self-care agency. Interventions need to ensure that such key aspect is included as part of the programme.

This is important as several studies have shown that family carers of people with dementia often experience 'symptoms' of burnout and stress ('feeling ill'),[19] but do not necessarily have a disease identified. If such symptoms however are not controlled, these are likely to lead to the onset of diseases (e.g. psychiatric morbidity, stress-related high blood pressure) and early mortality in the long-run.[35] Based on this review results, we recommend that future interventions in this area should be focused on promoting carers' ability to manage their own health and symptoms and 'self-care agency' to take action. Such skill is likely to translate into carers feeling prepared to manage several health behaviors, and not only physical exercise or specific diseases, for example, and therefore will have a higher impact.

Multicomponent interventions using individualized or person-centered approaches had an overall positive effect on carer outcomes.[36] The combination of telephone and one-to-one/group interventions also seemed to be beneficial. As most were from the United States, future interventions need to involve carers from a wider variety of cultural and ethnic backgrounds to establish the relevance and effectiveness of such programmes in different carer groups. Self-care practices are likely to vary according to the public resources available, family dynamics, social capital and health literacy. Promotion of health-related self-care thus requires an understanding of the individual own self-care practices and needs to be understood in the context of health care pluralism.[19] We thus argue that self-care behavior is a life-long issue which might be affected not only by providing care, but also to previous experiences with health and socioeconomic circumstances. Longitudinal, multi-level and multi-component interventions measuring the effects of several variables on health-promoting self-care and health outcomes are needed to better understand how these various factors inter-relate across time.

One of the largest RCTs included in this scoping review found no significant effects regarding care home placement, though it did improve carer quality of life, depression and problem behaviors in their relatives with dementia.[30] Even though this was a multicomponent intervention covering management of depressive symptoms, burden, self-care, healthy behaviors, social support and dementia behaviors, this may have failed to tackle carer ability to continue to provide care of the person with dementia at home. It may also have been that people being cared for had dementia too advanced at the time of the study, which meant that more carers in this study felt the need for residential care. This could also mean that the intervention may have helped carers prioritize their own needs, which may have led to easier acceptance of formal care and positive impact on carers' health and wellbeing. The lack of impact on care home

placement has nonetheless social and economic implications and the reasons for that should be further explored in future research.

Conclusions

This scoping review explored the potential benefits of health-promoting self-care interventions in family carers of people with dementia. A high heterogeneity was identified in the interventions in terms of methodology and the vast majority was conducted in the United States. None of the interventions had a particular focus on improving and measuring health-promoting self-care, but were rather related to areas that might be more broadly associated to health promotion and healthy lifestyle activities, such as physical exercise. Overall, interventions helped reduce carer depression and burden and increased quality of life, positive affect, physical activity and exercise self-efficacy. The expert panel considered this area of research important and recommend that future interventions should involve carers' preparedness and capacity to adhere to self-care practices. Future studies should use more specific validated tools to evaluate this construct so that a meta-analysis could be carried out to establish evidence of efficacy in relation to this. These should also be implemented with fidelity and should use a person-centered approach. A life-span and person-centered approach to health-promoting activities might be more likely to be successful with family carers.

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Competing interests

The authors declare that they have no competing interests.

Disclosure

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Authors' contributions

DO wrote the protocol, undertook study selection, data extraction, data analysis and wrote the paper. LS run the literature search, undertook study selection, data extraction, and writing the paper. MO helped to write the protocol and paper. All authors read and approved the final manuscript.

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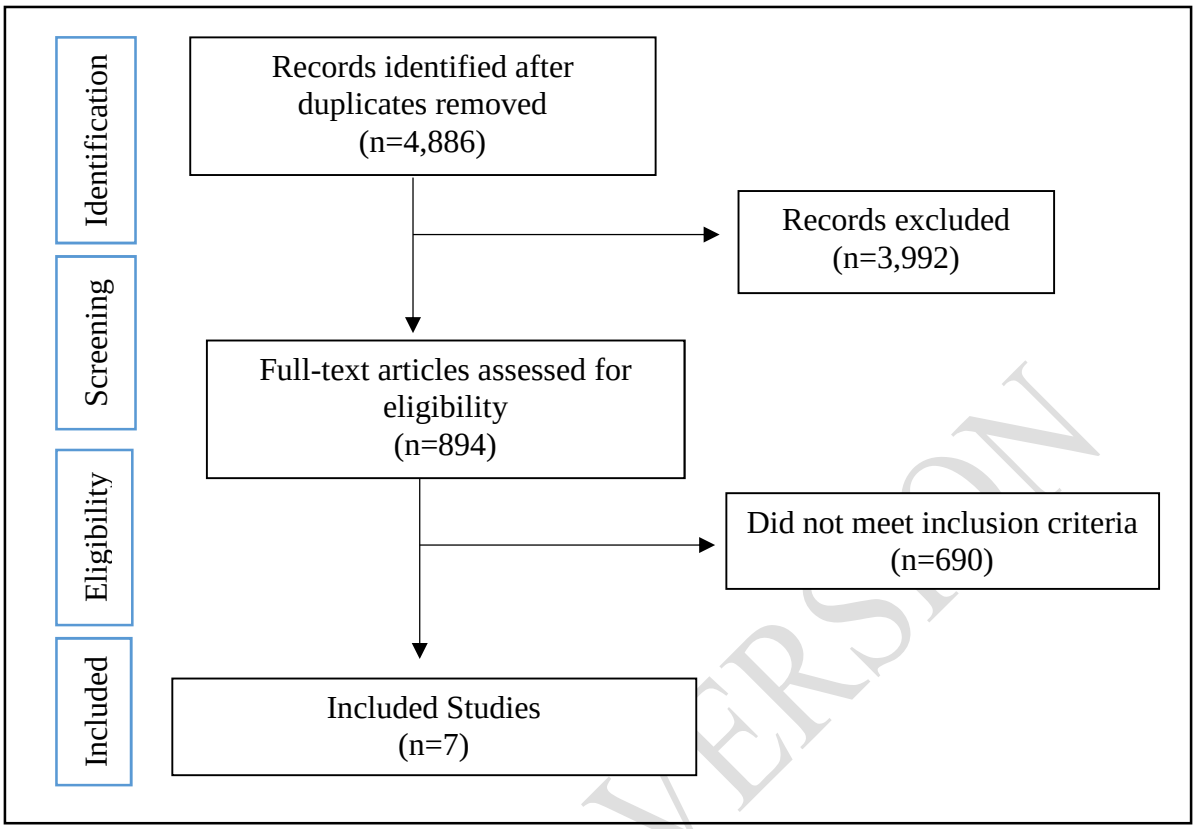

Figure 1. Flowchart showing the number of studies identified and selected for inclusion

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Table 1. Summary of interventions to increase health-promoting self-care behavior and physical exercise in carers of people with dementia (n=7)

Reference	Aim	Sample	Design	Intervention	Outcome measures and results
Farran et al.[24] United States	To test a carer skill building programme for managing dementia behavior	n=295	Randomized controlled trial	12-week session, 5 group sessions and 7 individualized telephone-based sessions about managing dementia behavior	Reduced depression in both groups (p<0.05), but no difference in efficacy
Belle et al.[30] United States	To test a structured multicomponent intervention in a diverse ethnic group of carers	n=642	Randomized controlled trial	12-month in-home and 6 telephone-based sessions of a carer skill building programme	Increased quality of life (p<00.1); reduced depression and problem behaviors in Latinos (p<0.001); no difference in care-home placement rates
Farran et al.[26] United States	To evaluate a health-promoting intervention designed to improve physical activity	n=211	Randomized controlled trial	Participation in physical activities for 12 months based on individual goals (telephone/ face-to-face)	Increased total physical activity at six (p=0.01) and 12 months (p=0.03); reduced burden (p=0.03) at three months
Connell and Janevic[25] United States	To evaluate a telephone-based exercise intervention	n=137	Randomized controlled trial	6-month telephone-based, physical exercise focused, intervention	Increased exercise levels (p<0.01) and exercise self-efficacy (p<0.01)
Farran et al.[27] United States	To develop and test a multicomponent Caregiver Skill Building web-based programme	n=100	Pilot study	Online-based modules: decreasing depressive symptoms and burden, improving self-care and social support, and managing behavioural symptoms	Positive evaluation of the programme; increased caregiving skill at 6/12 weeks (p=0.01 and p=0.05, respectively); reduced depression (p=0.01); increased positive affect at 6 weeks (p=0.05)
Teel and Leenerts[28] United States	To develop a theory-based intervention and to describe the process of evaluating the implementation	n=6	Pilot study	Telephone-based sessions by nurses: healthy habits, self-esteem, positive thoughts, avoiding overload, communication, building meaning and person-centered self-care strategies	Participants understood the content and planned to use the information Increased awareness about self-care
Lok and Bademli[29] Turkey	To test a self-care program on burden and healthy lifestyle	n=40	Pilot study	Seven sessions: strengthening the carer, decreasing burden and promoting healthy lifestyle	Reduced burden and increased healthy lifestyle behaviors

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Causes of poor health in carers of people with dementia

1. Health promoting self-care interventions are scarce and are not person-centered
2. High demands; limited time; long-term/burdensome care; social isolation; untreated mental and physical problems/symptoms
3. Carer old age
4. Problems with caregiving relationships, sense of obligation, guilt, lack of trust on services
5. Waiting until crisis point
6. The capacity to provide care and the carer health status are often not considered
7. Lack of regular breaks and knowledge about sources of support
8. Lack of national protocols for assessment and monitoring of carers' health needs

Health-promoting self-care interventions

1. Psychosocial interventions should focus on carers' expectations, goals, acceptance, their own needs and importance of self-care
2. Interventions should be person-centered and context specific to suit carers' preferences and needs, according to carers' age, access to support, length of time as carer, dementia stage, personality and coping resources and strategies
3. Blended approach interventions are useful (e.g. face-to-face and online, one-to-one and in groups)
4. Co-designed

Services should provide

1. Family-centered support
2. Assessment of capacity to provide care and to monitor status/ needs
3. More clinical specialists
4. Earlier identification and exposure to regular respite;
5. Education/strategies to monitor own well-being
6. Annual physical and mental health assessments ('health passport');
7. Welcoming and easy to use services;
8. An understanding, empathic and knowledgeable individual mentor

To measure effectiveness

1. Consider type of intervention and method of delivery
2. Outcome measures: self-care, functional decline, health care utilization, self-efficacy, well-being, depression, anxiety, burden, experience, quality of life, coping, preparedness to care, resilience and delay in institutional care (planned entry to long term care, as oppose to because of a crisis)

To optimize intervention success

1. Keep it flexible – day and time that is suitable for carers
2. Reduce power relationships
3. Provide a precise intervention dosage
4. Consider carer capacity and readiness to participate
5. Avoid 'one size fits all' approaches
6. Consider different dementia stages
7. Think carefully about how to frame the intervention (carers need to see the value in it): engagement is related to acceptance
8. Implement intervention with fidelity
9. Have the intervention well signposted in the wider society and local communities

Figure 2. Expert suggestions