ELSEVIER

Contents lists available at ScienceDirect

Asian Nursing Research

journal homepage: www.asian-nursingresearch.com



Review Article

Realist Review: Understanding Effectiveness of Intervention Programs for Dementia Caregivers



Youngran Tak, ¹ Junghee Song, ² Haeyoung Woo, ³ Jiyeon An^{4, *,★}

- ¹ College of Nursing, Hanyang University, Seoul, Republic of Korea
- ² Department of Nursing, Ansan University, Ansan, Republic of Korea
- ³ Department of Nursing, Gangneung-Wonju National University, Wonju, Republic of Korea
- ⁴ Department of Nursing, Kyungin Women's University, Incheon, Republic of Korea

ARTICLE INFO

Article history: Received 29 July 2018 Received in revised form 27 December 2018 Accepted 2 January 2019

Keywords: Caregivers Dementia Family Review

ABSTRACT

Purpose: Caring for patients with dementia is a challenging issue entailing heavy responsibility. Many interventions for caregivers have been developed, but their effectiveness is not clear. This study aimed to examine how, why, and under what circumstances interventions for dementia caregivers affected their burden of caring.

Methods: Authors used a realist review approach to explore the evidence for how different interventions reduce the burden of dementia caregivers. We completed the literature review about the burden of dementia caregivers and extracted the theoretical concepts to explain context-mechanism-outcome configuration why an intervention may be effective in some situations and not others. Six databases were searched for experimental or quasi-experimental studies conducted from 2008 to 2017. Of 1,225 screened studies, 10 studies were eligible for inclusion.

Results: None of the studies included all the derived contexts while explaining in detail the mechanism of the intervention effectiveness. Among contexts, the variable of other family members requiring care was not included in all studies. Among the analyzed studies, no studies have applied repeated intervention. Most studies included only some variables of context and mechanism, and these variables did not directly explain the effectiveness of intervention. The effect of outcome variables was significant for each study, and the effects of research intervention and national services could not be separately described.

Conclusion: Authors conclude that Korean culture's emphasis on relationships with others increases the burden of care. In context, Confucian norms and traditional femininity of Korea were reflected in the core. It is necessary to check the homogeneity of participants and the design of intervention to verify the effectiveness of the outcome variable of psychological burden.

© 2019 Korean Society of Nursing Science, Published by Elsevier Korea LLC. This is an open access article under the CC BY-NC-ND license (http://creativecommons.org/licenses/by-nc-nd/4.0/).

In recent years, dementia or Alzheimer's disease has become more prevalent around the world. The worldwide costs of dementia increased from US\$ 279 billion in 2000 to \$948 billion in 2016, with an annual growth rate of 15.94% [1]. The increased socioeconomic burden of dementia has led to an increase in interventions for caregivers. Family caregivers have emotional, social, and financial burdens, as well as having to complete routine, physically dangerous tasks related to caring for the demented family. This complex burden of caregivers can lead to cumulative stress and mental health problems, resulting in family disruption.

E-mail address: jyan030@kiwu.ac.kr

Interventions for the caregivers of dementia are economically beneficial because these interventions may delay the time a patient with dementia is institutionalized. Programs for caregivers can provide high-quality care or minimize burdens of caring, thereby enabling ongoing care [2]. Moreover, there has been greater emphasis on family-centered care, the core philosophy of 21st century health-care services, with increasing research on the burden on dementia caregivers [3]. Even though systematic review and meta-analysis of multiple intervention studies have sought to integrate evidence-based knowledge, there remains the question of whether we can trust the intervention studies that were examined. Because evidence-based practice entails applying study results from experimental settings to practical settings, a gap between experimental and everyday circumstances is inevitable, which implies that intervention research is sensitive to the situational

^{*} Correspondence to: Jiyeon An, PhD, RN, Department of Nursing, Kyungin Women's University, 63 Gyeyangsan-ro, Gyeyang-gu Incheon, 21041, Republic of Korea

^{*} ORCID: https://orcid.org/0000-0003-1964-3092

context. Realist reviews have accordingly emerged as a new method of systematic review to integrate intervention research in the area of evidence-based practice.

Therefore, to conduct an integrative review of intervention research related to the burden of dementia caregivers, this study applied a realist review method to analyze the literature, with a consideration of the situational contexts formed in patient-family relationships [4.5]. In South Korea, where family ties are especially important, the contexts within the caregiving family or the culture of Korean society are expected to affect the intervention outcomes. By analyzing intervention studies, the present study examined the effect that context has on the outcome and by what mechanism. Llanque et al [6] conducted a conceptual analysis of family stress in Alzheimer's dementia. The results are as follows: (1) Before the 1990s, the historical evolution of the concept of caregiver stress began with Walter Cannon in the 1930s. Lazarus and Folkman [7] emphasized the psychological domain of the individual's coping appraisals with stress. (2) After the 1990s, Pearlin et al [8] extensively analyzed the concept of caregiver stress: caregivers' objective and subjective outcomes may vary depending on the relationship and the intimacy with the patient with dementia. (3) In the 2000s, the term "caregiver's stress" has been used to describe this burden, and researchers have explored indicators of burden in the context of the caregiver. (4) Antecedents of caregiver stress include an accompanying disease with dementia, lack of support, constriction of the caregiver's social life, problematic behaviors of the care receiver, the duration of caregiving, and the cognitive and functional status of the care receiver.

As mentioned previously, the burden on caregivers who care for patients with dementia can be explained through its complex and multidimensional characteristics. In most intervention studies of the burden of dementia caregivers, the determinants affecting the outcomes can be classified into patient and family characteristics. Patient characteristics include behavioral problems, psychiatric symptoms, cognitive functional disorders, and lack of self-care/need of support. Family characteristics include caregiver role strains, caregiver physical/mental health, intrapsychic strains, and personality traits [9].

Variables related to the burden on dementia caregivers can serve as the components of an intervention program. Recently, psychosocial intervention (support, counseling, education, and skill training), case management, family compensation intervention, pharmacotherapy, communication intervention, and memory improvement intervention have been developed and used as interventions to reduce the burden on dementia caregivers [10]. Although several systematic reviews have examined intervention programs related to the burden on dementia caregivers, few metaanalyses have been performed because of the different research designs of the intervention studies. A meta-analysis of 46 studies of the burden on dementia caregivers revealed that only two studies (of respite care intervention and multicomponent intervention) showed a statistically significant positive effect [11]. A metaanalysis of 78 studies comparing the outcome variables of dementia caregivers showed that the effect of an intervention varied depending on its outcome variable (burden, depression, well-being, ability/knowledge, and patient symptoms) and was also affected by the patient's age, caregiver characteristics (adult child vs. spouse), and level of care (time, duration) [12]. These results suggest the importance of group homogeneity for group comparison research, among other design conditions. In other words, the social contextual characteristics of the participants in the study, which were either of caregiver roles or problematic care recipient behaviors, were important factors determining the effect of an intervention [13]. Because they have their own unique social systems and structures, humans respond differently to interventions in different circumstances. In an intervention study, the comparative group was statistically homogenous, but their real social contextual characteristics could not be the same [14]. Contextual considerations are particularly important when implementing evidence-based interventions. Core components of the context include need, precision, evidence, feasibility, skills/competence, cultural relevance, resources, and administrative and organizational support [15]. Nevertheless, in many intervention studies dealing with dementia caregivers, the group's context was not adequately considered apart from homogeneity.

Unlike a conventional systematic review or meta-analysis, a realist review, which is a new methodology for the integrative review of the literature, looks for contexts and mechanisms to suggest a new perspective by testing or refining a middle-range theory or by performing a pluralist interpretation of the intervention's effects [4]. In realist reviews, causality is not treated as a simple relationship between a cause and an effect but rather as a mechanism for how a cause brought about an effect. In particular, causal relationships among people are likely to be misinterpreted because they cannot be controlled experimentally, and complex intervention studies tend to imply a more multifactorial causality. Thus, a multidimensional study based on a realist review will be able to explain when an intervention is most effective and how its applicability can be maximized [5]. As per the standard guidelines of realistic reviews [4,5], causality comprises Intervention X, Outcome X, the mechanism connecting the intervention, and the outcome and context where the mechanism occurs. This is called the context-mechanism-outcome pattern configuration. The process of identifying, modifying, testing, and refining the context-mechanism-outcome (CMO) configuration $(C^*M = 0)$ through sequential and recursive analysis of the literature is the key process of realist review. Following the model of a realist review, this study aimed to develop our understanding of the evidence regarding interventions and their outcomes in caregivers and to evaluate whether the primary studies under review explained the respective mechanism with due consideration of the context of the caregiver and care receiver.

Methods

This study was conducted to analyze the CMO configuration that best explains the burden on dementia caregivers by applying the realist review method, based on scientific realism, to integrate and synthesize the results of published intervention studies to reduce caregiver burden. The study process was designed (Figure 1) with reference to the standard process for realist reviews proposed by Pawson et al [4] and Wong et al [5].

Identifying the review question

The purpose of this study was to identify the real, actual, and empirical factors shown to reduce dementia caregiver burden in a causal structure. The specific review questions were as follows: first, what are the characteristics of the research included in the analysis and the effects they found? The effect indicator was the burden on dementia caregivers, defined as psychosocial stress. Second, what are the mechanisms and contexts that caused the positive or negative effect on the research? Third, what should be considered when applying an intervention program for caregivers taking care of older people with dementia at home?

Initial theory and mechanism

Lazarus and Folkman's stress-coping theory [7] is the most representative among theories explaining dementia caregiver burden, whereby the degree to which an individual's adaptability buffers the strain or stress caused by his/her situation, supporting a patient with dementia determines the caregiver's outcome, which is the level of burden the caregiver feels.

Personal experience of stress depends on the way that an individual evaluates a situation and coping resources. During a stressful event, two cognitive processors become crucial to understanding the action and emotional states of an individual: primary cognitive appraisal, which involves evaluating the personal significance of a situation, and secondary cognitive appraisal, which involves evaluating the personal ability to cope with stressors [7].

On the other hand, Alzheimer's caregiver stress model by Pearling et al [8] is another representative theory explaining dementia caregiver burden. Their theory emphasizes the responsibilities of the dementia caregiver as a critical factor of his/her burden. These responsibilities are determined by the interaction between his/her environmental and individual characteristics. When there are fewer resources or coping strategies to buffer stress or the high demands of caregiving, the level of caregiver stress increases. The theory also explains the mediating effect of social support on the relationship between stress and caregiver outcomes.

Lazarus and Folkman's stress-coping theory [7] emphasizes individual situation and coping resources that can act as a stresscoping mechanism, whereas the Alzheimer's caregiver stress model by Pearling et al [8] emphasizes environmental characteristics, especially social support, as a stress-buffering mechanism.

Searching for and selecting primary studies

To identify the causal structure best explaining the phenomenon while ensuring cultural sensitivity regarding the complex and diverse interventions for dementia caregivers in Korea, the study set the strategy of searching six electronic databases (KISS, DBpia, Hakjisa Newnonmun, KMbase, NDSL, and RISS) from February to March 2017 using the same search strategy. The searches were updated in December 2017. We searched with MeSH terms (including entry terms) using the or/and combination. The search term was derived based on the PICO tool: population, intervention, comparison, outcomes. The search terms were as follows: (1) for population, "elderly", "old person", "old people", "older adults", "elders" "dementia," "Alzheimer's," "Alzheimer," "cognitive disorder," "care," "caregiving," "help," "support," and "family"; (2) for

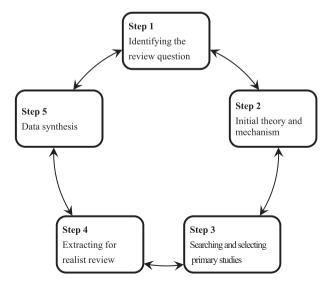


Figure 1. Five practical stages for the realist review based on of standards of Pawson et al [4] (2005) and Wong et al [5] (2013).

interventions, "education," "psychology," "training," "therapy," "self-help," "counseling," "exercise," "activity," "intervention," and "program"; and (3) for outcomes, "burden," "depression," "quality of life," "psychosocial stress," and "health." Theses and dissertations were excluded. To identify gray literature unavailable in journal databases, such as government reports and articles presented at seminars or symposiums, snowball searching was repeatedly performed using a Google search engine. Snowball searching continued until December 2017 so as to include all relevant literature. There were no restrictions placed on the publication language. However, to achieve the study's purpose of establishing a theoretical foundation reflecting Korea's cultural uniqueness, participants were limited to Koreans and interventions were limited to those conducted in Korea. Because the domestic and overseas constructions for the search strategy are different, only domestic search engines were used.

Extraction for the realist review

The period of extraction for the realist review was continuous and repeated from June to December 2017. All researchers agreed on the steps and criteria of extraction. The search process discovered 1225 potential articles for the analysis. After removing 357 theses/dissertations or duplicates, an additional 843 studies that did not meet the inclusion criteria were eliminated after reviewing the titles. For the remaining 21 articles, the abstracts were reviewed individually, after which another 11 studies were excluded because (1) they were review articles, (2) the intervention in the study was not for caregivers of patients with dementia. (3) the targets were patients living in nursing facilities rather than at home, or (4) the studies were published before 2008. One researcher selected articles in accordance with the inclusion criteria. Another researcher reviewed the selections, and the two researchers reached consensus through discussion. To homogenize the conditions of the intervention studies, the research period was limited to after 2008, when long-term care insurance services were initiated in Korea. Subsequently, 10 studies were selected for the final analysis [16-25] (Figure 2) (Table 1).

Data synthesis

The selected studies were analyzed according to their key variables, which were classified into context, mechanism, and outcomes. The key variables were derived mainly from the variables identified in initial theories and mechanisms, as well as from the influencing variables identified in previous research, limited by systematic reviews, meta-analysis, and literature reviews [11,12,26-31] (Table 2). The context variables were being a beneficiary of national services, severity of dementia, duration of morbidity, relationship with patient, presence of children requiring care, and place of residence. The mechanism variables were the length of the program, length of each session, type of intervention (group vs. individual), repetition of intervention, components of intervention, consideration of individual needs, and caregiver-only intervention. As for the outcomes, psychological variables including burden were analyzed (Table 3). We described the results in terms of explanations of the contexts and mechanisms based on the CMO configuration (Table 4).

Results

Context in primary research

As key contextual variables, the study selected and analyzed being a beneficiary of national services, patient characteristics

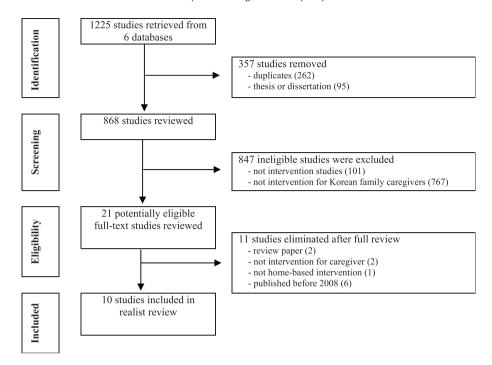


Figure 2. Flowchart of studies from identification to inclusion.

(severity, duration), family caregiver characteristics (relationship with the patient, children requiring care), and place of residence (Table 2). In all 10 selected studies, the participants were beneficiaries of national services (Table 4). The studies used convenience sampling among people with dementia and their families who were registered with dementia help centers or mental health centers and receiving services at the time of recruitment.

The burden on caregivers varied based on the severity of dementia. As the disease became more severe and problematic behaviors increased, the caregiver burden also increased. Duration of disease and duration of caregiving also influenced the outcome variable (burden on family caregivers). As the duration of disease lengthened, extending the duration of caregiving, the burden on caregivers increased [32]. Nonetheless, in terms of investigating the characteristics of patients with dementia, both of severity and duration were considered only in two studies each (number of study; 6, 7).

As for caregiver characteristics related to caregiver burden, the relationship with the patient and the presence of children requiring care were important. In previous studies, caregivers tended mostly

 Table 1
 Inclusion Criteria of Studies.

Data type	Inclusion criteria					
Participants	Family caregivers of people with dementia					
Language	Korean or English					
Study design	Experimental or quasi-experimental					
Intervention	Korean culture, home-based intervention for					
	family caregivers of patients with dementia,					
	group or individual approaches including					
	multidimensional approaches, support groups,					
	respite, training, psychotherapeutic approaches,					
	multicomponent approaches, case management,					
	online, offline, home visiting, education,					
	psychoeducation, social support, counseling,					
	intervention, program, service					
Primary outcome(s)	Psychosocial stress, burden, depression, quality					
	of life, health					
Publication year	2008–2017					

to be spouses, followed by daughters and then sons, and there was no literature on daughters-in-law or sons-in-law. In Korea, when a daughter-in-law or a son-in-law is involved in caregiving, the daughter-in-law thinks of her parents-in-law as her own family and participates in caregiving from a sense of responsibility which will lessen her husband's burden, whereas the son-in-law takes part in caregiving merely at his wife's request and does not expect his participation to reduce his wife's burden. When considering the relationship with the patient, the gender of the caregiver is very important. Women have a strong drive for multitasking and try to incorporate the role of nursing a patient with dementia (caregiver role) into their other roles. Men, however, draw a line between the

 Table 2 Main Variables for Context, Mechanism, and Outcome.

Category	Variables						
Context	Beneficiary of national services (C1)						
	 Severity of dementia (C2-1) 						
	 Duration of morbidity (C2-2) 						
	 Relationship with patient (C3-1) 						
	 Other family members requiring care (C3-2) 						
	 Place of residence of caregiver and patient (C4) 						
Mechanism	 Program of 8 weeks or more (M1) 						
	 90 minutes or more per session (M2) 						
	 Group intervention (M3) 						
	 Repeated application of intervention (M4) 						
	 Combination of education and support (M5) 						
	 Intervention considering demands of caregiver (M6) 						
	 Caregiver-only intervention (except patient) (M7) 						
Outcome	Psychosocial stress (including burden)						

Note. C1, beneficiary of national services; C2-1, severity of dementia; C2-2, duration of morbidity; C3-1, relationship with patient; C3-2, other family members requiring care; C4, place of residence of caregiver and patient; M1, program of 8 weeks or more; M2, 90 minutes or more per session; M3, group intervention; M4, repeated application of intervention; M5, combination of education and support; M6, intervention considering demands of caregiver; M7, caregiver-only intervention (except patient).

References of variables.

Acton and Kang [11], Sorensen et al [12], Laver et al [26], Vandepitte et al [27], Klein et al [28], Han et al [29], Dias et al [30], Chiao et al [31].

caregiver role and other roles, trying to reduce their nursing role when the time is limited. Consequently, female caregivers' nursing hours were markedly longer than those of male caregivers, which can lead to increased depression and burden among female caregivers. Thus, among the caregiver characteristics related to caregiver burden, the relationship with the patient was very important and nine studies (number of study; 2~10) described the relationship: spouses were the most common and most caregivers were female (Table 4). However, in terms of the intervention effect, there were no studies that analyzed the difference based on the relationship (spouse, son, daughter, daughter-in-law, others) with the patient.

Moreover, in terms of caregiver characteristics, the in-between generation bears a double burden. Caring for both a parent (patient with dementia) and a child (or children) is an important factor. In addition, in most cases, care is provided not by a single caregiver but by two or more caregivers, and conflict between them (due to differences in principles) affects the outcome. Only one study (number of study; 1) surveyed the presence of children without mention of whether the children needed care (Table 4).

The place of residence is also important because the types of services available and accessibility to the provider can differ depending on where the patient lives. Seven (number of study; 1, 2, 3, 5, 6, 7, 8) of the 10 studies indicated the place of residence of the patients and the caregivers, and most of the studies were conducted in metropolitan areas such as Seoul and Gyeonggi-do (Table 4).

Mechanisms in primary research

The goal of an intervention program is to reduce the burden experienced by dementia caregivers and to help them lead a healthy life. This study discovered the mechanisms of the intervention programs based on the causality of the effects.

The first mechanism is the time, duration, and repetition of the intervention. Most intervention programs required at least 8 weeks (eight sessions) to be effective. Sessions were more effective when they lasted longer than 90 minutes, and the effect increased when the intervention was repeatedly applied [10] (Table 2). Among the 10 studies analyzed, seven studies (number of study; 1, 2, 3, 7, 8, 9, 10) provided more than eight sessions of intervention and six studies (number of study; 1, 2, 3, 4, 8, 10) provided sessions longer than 90 minutes. However, there were no studies of repeated intervention provision (Tables 3 and 4).

The second mechanism is intervention program contents, such as an educational program to deliver knowledge about the disease and its treatment, a supportive program (including cognitive behavioral therapy and psychological counseling) to induce psychological changes, or a comprehensive program integrating both these aspects. Regarding the burden of dementia care, not only programs to relieve the psychological stress of caregivers but also programs delivering detailed information about symptoms, progress, and coping plans were able to ease caregivers' anxiety and change their ways of coping, eventually leading to reduced burden. A previous literature review regarding programs to reduce caregiver burden indicated that programs that combined education and support had more significant effects than education-only or support-only programs [33] (Table 2), and most studies analyzed in our research provided programs incorporating education, cognitive behavioral therapy, counseling, and psychological support (Table 3).

The third mechanism is whether the intervention program is based on an individual or a group approach. Individual approaches are easier to tailor to the needs of participants. However, in a group approach, the psychological support that comes from the support system naturally established between persons in similar

circumstances leads to more effective results in reducing caregiver burden [34]. Eight studies (number of study; 1, 2, 3, 4, 7, 8, 9, 10) provided group interventions (Tables 3 and 4).

The fourth mechanism is whether the content of the intervention program meets the needs of the patient and caregiver. Patients with dementia display various symptoms and reactions depending on the duration and progress of their disease, and patients and caregivers may have different demands regarding the intervention program due to the diversity of their socioeconomic environments. Therefore, tailored or customized intervention programs reflecting the diversity of the participants were found to be more effective [35]. Nonetheless, only three studies (number of study; 5,6,8) applied intervention programs reflecting individual needs (Table 4).

The last mechanism is separation from the patient during the intervention: whether the caregiver participates in the program alone or with the patient. The effect of separation can vary depending on the type of the program. For example, programs performed to improve patients' daily life skills and reduce problematic behaviors were more effective when patients were with their caregivers, whereas programs that promote the psychological stability of caregivers were more effective when conducted only for the caregivers apart from their patients [10]. Among the studies analyzed, nine studies (number of study; 1~4, 6~10) separated caregivers from patients when applying the intervention (Table 4). Only one study (number of study; 5) had both caregivers and patients participate together, probably because of the characteristics of the program: an intervention conducted to improve the daily life skills of patients with dementia through occupational therapy.

Outcomes in primary research

As the outcome variable, this study analyzed the effect on the components of dementia caregiver psychological variables (burden), such as subjective well-being, coping/adaptation, depression, quality of life, social support, self-esteem, and self-efficacy, as well as physical functional variables such as sleep. Among the 10 studies dealing with intervention programs for dementia caregiver burden, five studies (number of study; 3, 4, 5, 8, 10) had a significant psychological result on caregiver burden (Table 3).

Discussion

The most important point in the context is that the effects of intervention can vary with the situational characteristics of care receivers and caregivers and their interaction. These results suggest that it is necessary to consider individual contextual characteristics that affect the effectiveness of intervention rather than to use variables for statistical homogeneity. Contextual characteristics different from those of other countries include the Confucian culture of Korea and the ideology of women's expected behavior. Sacrifices for the family expected of women is a factor increasing the burden of care. Studies conducted in the Asian countries of Japan and China have not shown the impact of cultural characteristics on the burden of caregivers and the relationship between patients and caregivers, but their gender ratio and average age were similar to those of studies conducted in Korea. The average age of caregivers was 52.5 years and 53.4% of them were female in Japanese studies. Japanese caregivers of the family with dementia were older and more likely to be female in the 2012 Japan National Health and Wellness Survey [36]. Similarly, Chinese studies show that most caregivers were female (56.6%). The most common caregiver relationship to the patient with dementia was spouse (51.9%), followed by son (33.2%) and daughter (9.2%) [37].

 Table 3 Primary Research for Realist Review.

Stu	dies (year)	Method			Result		
		Design	Age of caregivers	Duration	Contents (individual vs group)	Instructor	
1	Kim & Han (2016)	 Quasi-experimental Experiment (n = 7)	Mean: 66.4 years	1 per week 2 hours (total 33 wks)	Supporting and counseling (Group)	No mention	Depression (+) Other variable (-): suicide ideation, self-esteem, hope, entrapment, affect)
2	Kim & Lim (2016)	Quasi-experimentalExperiment (n = 6)	60s~80s	1 per week 1.5 hours (Total 8 wks)	Meditation and counseling (Group)	Nurse	Burden (–), Depression (+) Self-esteem (+)
3	Cheon et al (2011)	 Quasi-experimental Experiment (n = 19) Control (n = 22) 	30s~70s	1 per week 2 hours (total 8 wks)	Education and supporting (Group)	Nurse	Burden (+), Subjective wellbeing (+) Social support (+)
4	Lee et al (2013)	 Quasi-experimental Experiment (n = 19) a subgroup (spouse/children/daughter-in-law) 	34~76 years	1 per week 1.5 hours (total 4 wks) ^a F/U: 2 mon	Cognitive behavioral therapy (Group)	Clinical psychologist	Burden (+), Abuse behavior (+) Coping (+), Depression (+) ^a F/U: Burden (+)
5	Hwang et al (2011)	 Quasi-experimental Experiment (n = 30) a subgroup (patient n = 15 and family n = 15) 	30s~70s	2 per week (home visit and telephone) (total 7 wks)	Education and activity aids (motor and process skill) (individual)	Occupational therapist	Burden (+)
6	Jang & Choi (2016)	 Quasi-experimental Experiment (n = 15) Control (n = 21) 	30s~80s	30~50 min education & 2 times telephone during 4 wks	Education and telephone counseling (individual)	Nurse	Self-efficacy (+), Coping (+) Knowledge (+), Preparedness (+)
7	Song & Jo (2014)	 Quasi-experimental Experiment (n = 11)	40s~70s	1 per week 1 hours (total 9 wks)	Cognitive behavioral therapy (Group)	Nurse	Burden (-), Sleep (-) Depression (+), Quality of life (+)
8	Park et al (2015)	 Quasi-experimental Experiment (n = 17) Control (n = 17) 	Mean: 64.7 years	1 per week 1.5 hours (total 8 wks)	Psychoeducation (Group)	Nurse Social worker	Burden (+), Depression (+) Coping (-)
9	Bang & Kim (2016)	 Quasi-experimental Experiment (n = 18) Control (n = 18) 	Mean: 62.8 years	1 per week 1 hours (total 8 wks)	Supporting for communication (Group)	Nurse	Burden (-), Resilience (+) Adaptation (+), Perceived health (+) Depression (-)
10	Lee & Kim (2017)	 Quasi-experimental Experiment (n = 26) Control (n = 26) 	Older than 60 years: 42.3%	1 per week 1.5 hours (total 8 wks)	Education (Group)	Nurse	Burden (+), Depression (+) Dementia recognition (+)

Note. F/U = follow up; wks = weeks.

a Subgroup.

Table 4 Context-Mechanism-Outcome configuration from Analysis of Primary Research.

Studies		Context					Mechanism							Outcome			
		C1	C1	C1	C2		C3		C4	M1	M2	М3	M4	M5	M6	M7	
			C2-1	C2-2	C3-1	C3-2											
1	Kim & Han (2016)	0	×	×	×	0	0	0	0	0	×	0	×	0	PS		
2	Kim & Lim (2016)	0	×	0	0	×	0	0	0	0	×	×	×	0	PS		
3	Cheon et al (2011)	0	×	×	0	×	0	0	0	0	×	0	×	0	S		
4	Lee et al (2013)	0	0	×	0	×	×	×	0	0	×	0	×	0	S		
5	Hwang et al (2011)	0	0	×	0	×	0	×	×	×	×	×	0	×	S		
6	Jang & Choi (2016)	0	0	0	0	×	0	×	×	×	×	0	0	0	S		
7	Song & Jo (2014)	0	0	0	0	×	0	0	×	0	×	0	×	0	PS		
8	Park et al (2015)	0	×	0	0	×	0	0	0	0	×	0	0	0	PS		
9	Bang & Kim (2016)	0	×	0	0	×	×	0	×	0	×	×	×	0	PS		
10	Lee & Kim (2017)	0	×	×	0	×	×	0	0	0	×	0	×	0	S		

Note. C = context; M = mechanism; S = significant; PS = partial significant.

C1, beneficiary of national services; C2-1, severity of dementia; C2-2, duration of morbidity; C3-1, relationship with patient; C3-2, other family members requiring care; C4, place of residence of caregiver and patient; M1, program of 8 weeks or more; M2, 90 minutes or more per session; M3, group intervention; M4, repeated application of intervention; M5, combination of education and support; M6, intervention considering demands of caregiver; M7, caregiver-only intervention (except patient).

In Korea, the filial piety of Confucianism is embedded in the nation's cultural value system and obliges families supporting patients with dementia to play an obsessive caregiving role. Role expectations for family members are strictly fixed. Parents' blind sacrifice for their children and, in return, children's unconditional filial duty to their parents is a key link in Korean family relationships. Koreans feel a sense of duty to care for their parents diagnosed with dementia at home and cannot ask for proper help due to the sense of obligation whereby they have to be responsible for their parents, even if they are threatened by the process of caregiving. When a woman marries, she becomes a direct relative to her husband's parents and tends to fulfill her husband's filial duty on his behalf after marriage. In fact, daughters-in-law complain of greater caregiver burden or health problems (e.g., depression) than other caregivers do, being classified as a higher risk group [38]. A daughter's caregiving is in return for her parents' sacrifice, whereas a daughter-in-law's caregiving is motivated by her desire to maintain her relationship with her husband. The daughter's obligation to care for parents with dementia is a cause of psychological stress. In a previous study, daughters with many leisure activities showed high levels of guilt and high scores in depression symptoms. Therefore, among the determinants of the dementia burden, the gender of the caregiver is important, and especially if the caregiver is a female family member (wife, daughter, daughterin-law), she may have a negative health status that interacts with other risk factors [39].

Moreover, when the caregiver is a middle-aged woman, she tends to experience higher levels of psychological stress than a male caregiver does because in most cases she also must take care of her children [29]. Because materialism is highly emphasized in Korean culture, mothers tend to sacrifice more than fathers do in terms of child-rearing. Because the traditional Korean value of filial piety, combined with Confucian tradition, has deviated from its essence into restrictions for women, the burden on female caregivers of patients with dementia should be understood not as being due to an individual's psychological vulnerability but rather the obligations of social norms. Therefore, future intervention research on dementia caregiver burden should classify caregivers by gender and compare the intervention effects, rather than performing a simple statistical calibration of the participants' gender. If gender is not homogeneous, the effect of an intervention for dementia caregivers may reflect participant bias due to gender differences.

Meanwhile, traditional theories on dementia caregiver burden emphasize caregivers' individual characteristics in the process of cognizing, appraising, and adapting to stressful situations. Although the level of burden can differ based on the caregivers' characteristics, such as stress level, strain, and psychopathologic distress, there can be large personal variations depending on the characteristics of the relationship with the patient. Usually, while intervention research examines the demographic characteristics of the patients and the caregivers to verify the homogeneity between the experimental and control groups, in fact, the interrelation between the patient's and caregiver's characteristics may have another effect. For instance, when a daughter is caring for a parent with dementia, the caregiving burden can vary widely between a daughter who lived with her parent before the dementia diagnosis and one who moved in after the diagnosis. For the former, adapting to changes that occur after the diagnosis is important, whereas, for the latter, adapting to living with her parent may be more critical. Although the patient's daughter is the caregiver in both cases, the type and level of burden on the daughter differs, which may lead to the same intervention having different effects. In this study, the relationship with the patient and the presence of other family members requiring care were critical contexts in explaining the effects of interventions for dementia caregivers in Korea, where family relationships are highly valued.

Dementia caregiver burden can be defined as a state where the caregiver is unable to pursue his/her comfort; in other words, it is a pathological state of tension in body and mind. From the perspective of nursing science, comfort refers to respite, and the burden on dementia caregivers is a constant state of tension without respite. The long-term care policies of Korea, as well as those of other countries, are based on the concept of respite services to reduce family caregivers' burden. There should be a national policy for families with dementia, and it is important to integrate it with a support system for effective delivery such as financial support and direct care service.

Among the mechanisms analyzed in the study, the application of caregiver-only intervention can be explained as a process of controlling exogenous variables. Separation from the patient during intervention can be classified as physical separation and psychological separation. If the caregiver worries about the patient during the intervention, he/she is not psychologically separated from the patient, despite the physical separation, and thus, the intervention may not have a significant effect. The identified mechanisms, such as an intervention period of eight weeks or more, sessions over 90 minutes, and repeated application of the intervention, show that respite is a hidden effect of intervention, in that the respite time increases proportionately to the intervention time. Furthermore, previous research has also shown that the burden on Alzheimer's caregivers is directly

affected by the patient's cognitive function and the duration of care [40].

The outcome variable in this study was the burden on caregivers. By definition, caregiver burden is the perceived stress and fatigue associated with caring for a person who needs special nursing services. Intervention for dementia caregivers should take the form of combined education and support that reflect the needs of caregivers, because the burden level depends on how individuals perceive and appraise the caregiving situation. Educational intervention alone cannot reduce burden. The burden on dementia caregivers can only be lessened when caregivers change how they perceive the stressful caregiving situation, which is unpredictable and specific to the individual. Therefore, it is desirable to provide psychologically supportive intervention alongside other intervention programs. Moreover, tailored intervention that takes into account the demands or needs of caregivers is the proper mechanism to reduce caregiver burden.

Limitations and strengths

The limitations of this study are similar to those of other systematic literature reviews. Owing to limitations in search terms and databases, the selection of analyzed articles may not be comprehensive. There is also the possibility of bias in generalization and the exclusion of gray literature. For example, as per the inclusion criteria, only studies published in academic journals were included in the analysis, thereby excluding many high-quality unpublished theses or dissertations. Moreover, many researchers give priority to publishing significant results, which may result in publication bias. In the process of synthesizing the selected studies, it was difficult to identify the contexts and mechanisms because some studies did not describe the method in detail. There were also some unclear cases. In one study, it was uncertain whether participants were daughters or sons. Another study had no description of whether the person performing the intervention was a nurse or another professional, and one study only described the intervention period as eight sessions over 8 weeks, without specifying the interval. Moreover, one study simply stated that the age of the patients was over 65, without giving the proportions of aged and hyperaged (over 80) patients.

Nevertheless, this study shows that there are relatively few intervention studies involving families affected by dementia and that Korea's cultural characteristics are not sufficiently reflected in intervention studies. The most important aspect of the intervention study is that the program framework should be fully examined by identifying what characteristics of the program are relevant to the outcome variables. In addition, this study suggests it is necessary to continuously validate theories of the burden on dementia family caregivers and to apply full rigor when designing experiments for intervention research.

Conclusion

The main conclusion of the study is that even if intervention studies are extracted based on clearly predefined criteria, the individual and environmental characteristics of the patients with dementia and their families are inevitably heterogeneous. In particular, unlike Western countries, the environmental situations in Korea are multilayered. Although the influences of the microsystem, mesosystem, exosystem, and macrosystem surrounding an individual are relatively small in Western countries, where people put more value on individuality, these systems have a strong influence in Korea, where relations with others are valued more highly. In Korea, social norms, universal values, and national norms included in the macrosystem have a significant

influence on people's belief systems, which aggravates the caregiver burden caused by filial piety and patriarchal Confucianism. Even the participants who were assumed to be homogeneous in a study, based on a test of homogeneity, cannot be truly homogeneous because of the heterogeneity of the multilayered system surrounding them.

In addition, this study confirmed that intervention programs for dementia caregivers in Korea remain heterogeneous. To establish a standard intervention for dementia caregivers, more intervention research should be conducted. In addition, a balance between efficiency and sensitivity is needed when designing experiments to simultaneously minimize bias and boost intervention effectiveness. In Korea, providing care for a patient with dementia implies a concept of obsessive caregiving distorted by filial piety and patriarchal Confucianism. For this reason, we cannot expect a one-off intervention to reduce the burden on family caregivers. There is an urgent need to develop policy-linked intervention programs and to accumulate reliable results through repeated research. Moreover, the integration of research findings based on ontological objectivism should be pursued using the realist review method, as in the present study. However, care should be exercised in interpreting the results of this study, because they reflect the perspectives of the researchers, an inevitable trait of a review article, and thereby entail the possibility of research bias on cultural or policy issues.

Conflicts of interest

The authors declare that they have no conflicts of interest.

Funding statement

This research was supported by the Basic Science Research Program through the National Research Foundation of Korea (NRF) funded by the Ministry of Science, ICT & Future Planning (Grant No. 201500000002876).

Acknowledgments

The authors thank their colleagues from the ministry of Science, ICT & Future Planning, which provided insight and expertise that greatly assisted the research.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.anr.2019.01.002.

References

- 1. Xu J, Zhang Y, Qiu C, Cheng P. Global and regional economic costs of dementia: a systematic review. Lancet. 2017;390(4):S47. https://doi.org/10.1016/S0140-6736(17)33185-9
- Petriwskyj A, Parker D, O'Dwyer S, Moyle W, Nucifora N. Interventions to build resilience in family caregivers of people living with dementia: a comprehensive systematic review. JBI Database Syst Rev Implement Rep. 2016;14(6):238–73. https://doi.org/10.11124/jbisrir-2016-002555
- Boltz M, Chippendale T, Resnick B, Galvin JE. Testing family-centered, functionfocused care in hospitalized persons with dementia. Neurodegener Dis Manag. 2015;5(3):203–15. https://doi.org/10.2217/nmt.15.10
- Pawson R, Greenhalgh T, Harvey G, Walshe K. Realist review—a new method of systematic review designed for complex policy interventions. J Health Serv Res Policy. 2005;10(1):21–34. https://doi.org/10.1258/1355819054308530
- Wong G, Greenhalgh T, Westhorp G, Buckingham J, Pawson R. RAMSES publication standards: realist syntheses. BMC Med. 2013;11:21. https://doi.org/10.1186/1741-7015-11-21
- Llanque S, Savage L, Rosenburg N, Caserta M. Concept analysis: Alzheimer's caregiver stress. Nurs Forum. 2016;51(1):21–31. https://doi.org/10.1111/nuf.12090

- Lazarus RS, Folkman S. Stress, appraisal, and coping. New York, NY: Springer; 1984, p. 22–52.
- Pearlin LI, Mullan JT, Semple SJ, Skaff MM. Caregiving and the stress process: an overview of concepts and their measures. Gerontologist. 1990;30(5):583–94. https://doi.org/10.1093/geront/30.5.583
- Van der Lee J, Bakker TJ, Duivenvoorden HJ, Dröes RM. Multivariate models of subjective caregiver burden in dementia: a systematic review. Aging Res Rev. 2014;15:76–93. https://doi.org/10.1016/j.arr.2014.03.003
- Dupuis SL, Epp T, Smale B. Caregivers of persons with dementia: roles, experiences, supports and coping: a literature review. In: Murray Alzheimer research and education program. University of Waterloo MAREP; 2004 [cited 2018 Jun 3]. Available from: http://www.helpingyoucare.com/wp-content/uploads/2010/11/Caregivers-of-Persons-with-Dementia-Roles-Experiences-Supports-and-Coping-A-Literature-Review.pdf
- 11. Acton GJ, Kang J. Interventions to reduce the burden of caregiving for an adult with dementia: a meta-analysis. Res Nurs Health. 2001;24(5):349–60. https://doi.org/10.1002/nur.1036
- Sörensen S, Pinquart M, Duberstein P. How effective are interventions with caregivers? An updated meta-analysis. Gerontologist. 2002;42(3):356–72. https://doi.org/10.1093/geront/42.3.356
- Givens JL, Mezzacappa C, Heeren T, Yaffe K, Fredman L. Depressive symptoms among dementia caregivers: role of mediating factors. Am J Geriatr Psychiatry. 2014;22(5):481–8. https://doi.org/10.1016/j.jagp.2012.08.010
- Wong G, Westhorp G, Manzano A, Greenhalgh J, Jagosh J, Greenhalgh T. RAMESES II reporting standards for realist evaluations. BMC Med. 2016;14:96. https://doi.org/10.1186/s12916-016-0643-1
- Horner R, Blitz C, Ross SW. The importance of contextual fit when implementing evidence-based interventions. Washington, DC: Office of the Assistant Secretary for Planning and Evaluation, Office of Human Services Policy, US Department of Health and Human Services; 2014. p. 1–16. https://aspe.hhs.gov/system/files/pdf/77066/ib_Contextual.pdf
- Kim SL, Han SJ. Development and effectiveness of an applied art psychological counseling program for family care-givers of elderly with dementia. Asia Pac J Multimedia Servs Converg Art Human Soc. 2016;6(4):141–50. https://doi.org/10.14257/AJMAHS.2016.04.32. Korean.
- 17. Kim M, Lim KC. Effects of Dongsasub training for family caregivers of patients with dementia on their burden, depression, and self-esteem. J Muscle Jt Health. 2016;23(1):9–18. https://doi.org/10.5953/JMJH.2016.23.1.9. Korean.
- Cheon SH, Chang SO, Kong GS, Song MR. Development and evaluation of a community-based respite program for family caregivers of elders with dementia. J Korean Acad Fundam Nurs. 2011;18(3):337–47. Korean.
- Lee SA, Lee MH, Chi YK, Han JW, Park JY, Kim TH, et al. Cognitive-behavioral program for care-givers of the elderly with dementia: preliminary study. Korean J Clin Psychol. 2013;32(4):853–74. Korean.
- Hwang YJ, Jeong WM, Lee KS, Lim HK, Kim DJ. Effects of a tailored occupational activity program applied to patients with dementia and their caregivers in the community. J Korean Gerontol Soc. 2011;31(1):129–41. Korean.
- 21. Jang J, Choi H. The effects of emotion-focused individual intervention for family caregivers of people with early stages of dementia. J Korean Acad Psychiatr Ment Health Nurs. 2016;25(2):101–12. https://doi.org/10.12934/jkpmhn.2016.25.2.101. Korean.
- 22. Song EJ, Jo HK. Effects of the "Happy Plus Program" for family caregivers of patients with dementia on sleep, depression, burden, and quality of life of caregivers. J Korean Acad Psychiatr Ment Health Nurs. 2014;23(2):49–59. https://doi.org/10.12934/jkpmhn.2014.23.2.49. Korean.
- 23. Park M, Park MH, Kim HH. Effects of a multimodal psychoeducational program on burden, depression, and problem coping behaviors in family caregivers of patients with dementia. J Korean Gerontol Nurs. 2015;17(1):10–9. https://doi.org/10.17079/jkgn.2015.17.1.10. Korean.
- Bang M, Kim O. Effect of the family resilience reinforcement program for family caregivers of the elderly with dementia. Korean J Adult Nurs. 2016;28(1): 71–82. https://doi.org/10.7475/kjan.2016.28.1.71. Korean.

- Lee SA, Kim HS. Effects of a dementia family education program for dementia recognition, burden, and depression in caregivers of elderly with dementia. J Korean Acad Psychiatr Ment Health Nurs. 2017;26(1):14–23. https://doi.org/10.12934/jkpmhn.2017.26.1.14. Korean.
- Laver K, Milte R, Dyer S, Crotty M. A systematic review and meta-analysis comparing care focused and dyadic multicomponent interventions for carers of people with dementia. J Aging Health. 2017;29(8):1308–49. https://doi.org/10.1177/0898264316660414
- Vandepitte S, Van den Noortgate N, Putman K, Verhaeghe S, Faes K, Annemans L. Effectiveness of supporting informal caregivers of people with dementia: a systematic review of randomized and non-randomized controlled trials. J Alzheimers Dis. 2016;52(3):929–65. https://doi.org/10.3233/JAD-151011
- Albrecht D, Pendergrass A, Becker C, Hautzinger M, Pfeiffer K. Dementia caregiver interventions: a systematic review of care recipient outcome measures. Int J Emerg Ment Health. 2015;17(2):415–26. https://doi.org/10.4172/1522-4821.1000186
- 29. Han SJ, Lee S, Kim JY, Kim H. Factors associated with family caregiver burden for patients with dementia: a literature review. J Korean Gerontol Nurs. 2014;16(3):242–54. https://doi.org/10.17079/jkgn.2014.16.3.242. Korean.
- Dias R, Santos RL, Sousa MF, Nogueira MM, Torres B, Belfort T, et al. Resilience of caregivers of people with dementia: a systematic review of biological and psychosocial determinants. Trends Psychiatry Psychother. 2015;37(1):12–9. https://doi.org/10.1590/2237-6089-2014-0032
- 31. Chiao CY, Wu HS, Hsiao CY. Caregiver burden for informal caregivers of patient with dementia: a systematic review. Int Nurs Rev. 2015;62(3):340–50. https://doi.org/10.1111/inr.12194
- Moishi E, Foxe D, Leslie F, Savage S, Hsieh S, Miller L, et al. The impact of dementia severity on caregiver burden in frontotemporal dementia and Alzheimer disease. Alzheimer Dis Assoc Disord. 2013;27(1):68–73. https://doi.org/10.1097/WAD.0b013e318247a0bc
- 33. Bakker TJ, Duivenvoorden HJ, van der Lee J, Olde Rikkert MG, Beekman AT, Ribbe MW. Benefit of an integrative psychotherapeutic nursing home program to reduce multiple psychiatric symptoms of psychogeriatric patients and caregiver burden after six months of follow-up: a reanalysis of a randomized controlled trial. Int Psychogeriatr. 2013;25(1):34—46. https://doi.org/10.1017/S1041610212001305
- Martín-Carrasco M, Ballesteros-Rodríguez J, Domínguez-Panchón AI, Muñoz-Hermoso P, González-Fraile E. Interventions for caregivers of patients with dementia. Actas Esp Psiquiatr. 2014;42(6):300–14.
- Jennings LA, Reuben DB, Evertson LC, Serrano KS, Ercoli L, Grill J, et al. Unmet needs of caregivers of individuals referred to a dementia care program. J Am Geriatr Soc. 2015;63(2):282–9. https://doi.org/10.1111/jgs.13251
- Goren A, Montgomery W, Kahle-Wrobleki K, Nakamura T, Ueda K. Impact of caring for persons with Alzheimer's disease or dementia on caregivers' health outcome: findings from a community based survey in Japan. BMC Geriatr. 2016;16:122. https://doi.org/10.1186/s12877-016-0298-y
- 37. Tang B, Harary E, Kurzman R, Mould-Quevedo JF, Pan S, Yang J, et al. Clinical characterization and the caregiver burden of dementia in China. Value Health Reg Issues. 2013;2(1):118–26. https://doi.org/10.1016/j.vhri.2013.02.010
- Lee J, Sohn BK, Lee H, Seong S, Park S, Lee JY. Impact of behavioral symptoms in dementia patients on depression in daughter and daughter-in-law caregivers. J Womens Health. 2017;26(1):36–43. https://doi.org/10.1089/jwh.2016.5831
- Romero-Moreno R, Losada A, Margquez M, Laidlaw K, Fernández-Fernández V, Nogales-Gonzáles C, et al. Leisure, gender, and kinship in dementia caregiving: psychological vulnerability of caregiving daughters with feelings of guilt. J Gerontol B Psychol Sci Soc Sci. 2014;69(4):502–13. https://doi.org/10.1093/geronb/gbt027
- Yu H, Wang X, He R, Liang R, Zhou L. Measuring the caregiver burden of caring for community-residing people with Alzheimer's disease. PLoS One. 2015;10(7):e0132168. https://doi.org/10.1371/journal.pone.0132168