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Dementia Caregivers and Cognitive Behavioral Therapy: A Systematic Review

Demans Tanısı Olan Kişilere Bakım Verenler ve Bilişsel Davranışçı Terapi: Sistematik Derleme

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Abstract

Dementia is seen in increasing numbers, and people diagnosed with dementia need other people's care. Caregivers are generally family members of the person and may experience psychological difficulties and may need psychological help. Therefore, the aim of this study is to investigate the effectiveness of Cognitive Behavioral Therapy (CBT) based interventions applied to family caregivers of people with dementia. In order to review CBT based interventions for family caregivers of people with dementia, researches published between 1990-2020 in EBSCHOHost (including Medline), Web of Science and Cochrane (including PubMed and Embase) databases were scanned. These screening and reporting were carried out in accordance with the PRISMA Statement used in reporting systematic reviews. In the first identification, 819 studies were obtained. When repeated studies were excluded, considering the inclusion and exclusion criteria, 20 studies were included for this review. It was determined that CBT based interventions can be applied individually and as a group, and these applications can also be carried out face-to-face, via telephone and the Internet. Although the duration, frequency and evaluations of the sessions differ in the studies, it is seen that CBT interventions have positive contributions to family caregivers of people with dementia, dementia patients receiving care, and communication between them. When evaluated in general, it is concluded that CBT is effective for family caregivers of people with dementia. The findings of the studies were discussed in the light of the related literature and suggestions were made for future studies.

Keywords: Cognitive behavioral therapy, caregivers, dementia, Alzheimer disease, systematic review

Öz

Demans her geçen gün artan sayılarda görülmektedir ve demans tanısı alan kişiler başka insanların bakımına ihtiyaç duymaktadırlar. Bakım verenler ise genelde kişinin aile üyeleri olmaktadır. Bakım verenler psikolojik sıkıntılar yaşayabilmekte ve psikolojik yardıma ihtiyaç duyabilmektedirler. Bu nedenle bu çalışmanın amacı demans tanısı olan kişiye bakım veren aile üyelerine uygulanan Bilişsel Davranışçı Terapi temelli müdahalelerin etkisinin incelenmesidir. Demans tanısı olan kişiye bakım veren aile üyelerine yönelik Bilişsel Davranışçı Terapi temelli müdahalelerinin gözden geçirilmesi amacıyla EBSCHOHost (Medline dahildir), Web of Science ve Cochrane (PubMed ve Embase dahildir) veri tabanlarında 1990-2020 yılları arasında yayınlanmış araştırmalar, ilgili anahtar kelimelerle taranmıştır. Bu tarama ve raporlama sistematik derlemelerin rapor edilmesinde kullanılan PRISMA Bildirimi'ne uygun olarak yürütülmüştür. İlk belirlemede 819 çalışmaya ulaşılmıştır. Tekrar eden çalışmalar çıkarıldığında, dahil etme ve dışlama kriterleri göz önünde bulundurulduğunda 20 çalışma bu derlemeye dahil edilmiştir. Bilişsel Davranışçı Terapi temelli müdahalelerin bireysel ve grup olarak uygulanabildiği ve bu uygulamaların yüz yüze, telefon ve internet aracılığıyla yapıldığı tespit edilmiştir. Çalışmalarda seansların süresi, sıklığı ve yapılan değerlendirmeler farklılık gösterse de Bilişsel Davranışçı Terapi müdahalelerinin demans tanısı olan kişiye bakım veren aile üyelerine, bakım alan demans tanısı olan kişilere ve iletişimlerine olumlu katkılarının olduğu görülmektedir. Genel olarak değerlendirildiğinde, Bilişsel Davranışçı Terapinin demans tanısı olan kişilere bakım veren aile üyeleri için etkili olduğu sonucuna ulaşılmıştır. Çalışmaların bulguları ilgili alanyazın ışığında tartışılmış olup, gelecek çalışmalar için önerilerde bulunulmuştur.

Anahtar sözcükler: Bilişsel davranışçı terapi, bakım veren, demans, Alzheimer hastalığı, sistematik derleme

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DEMENTIA is very common today. It was determined that there were 47.47 million people with dementia in the world in 2015. It is predicted that the number of people diagnosed with dementia will increase day by day, with 75.63 million in 2030 and 135.46 million in 2050 (Alzheimer Disease International 2013). Even more striking, a new case emerges every 4.1 minutes (WHO 2015). Although the diagnosis of dementia is based on certain criteria (WHO 1992, APA 1994), the most basic criterion is the deterioration in individuals' memories, thoughts, behaviors and their ability to continue their daily lives (WHO 2019).

The majority of people diagnosed with dementia are given home care by their family members. Family caregivers of people with dementia provide a wide range of services such as feeding, dressing, taking a bath and taking them to the toilet (Alzheimer's Association 2004). It is stated that half of the family caregivers of people with dementia spend at least 46 hours a week for caregiving (Schulz et al. 2003) and experience difficulties in allocating time to them, going to the doctor, shopping, walking and cooking (Altuntaş and Koç 2015). In summary, the prevalence of dementia is increasing day by day, and those diagnosed need a person to care for them. While caregivers offer many services, they may have problems in terms of sustaining their own lives.

Given that caregiving takes long hours and affecting caregivers' own lives, it seems inevitable that caregiving negatively affects caregivers. Generally, caregiving negatively affects the psychological health of caregivers. Family caregivers of people with dementia report high levels of stress (Oyebode 2003, Gilhooly et al. 2016), psychological distress (Stall et al. 2019), depression (Covinsky et al. 2003) and anxiety (Liu et al. 2017). The fact that caregiving affects the psychological health of individuals increases the importance of psychological interventions for family caregivers of people with dementia. In addition, family caregivers of people with dementia stated that they need psychological help most (Soner and Aykut 2017). Cognitive Behavioral Therapy (CBT) is one of the interventions for family caregivers of people with dementia, although there are a variety of intervention. CBT involves developing cognitive and behavioral skills that help individuals cope with stressful and difficult situations, and is one of the top interventions that are effective for family caregivers of people with dementia (Gallagher-Thompson and Coon 2007).

Although there are many studies related to CBT for family caregivers of people with dementia (eg Wilz and Soellner 2016, Barnest and Markham 2018, Meichsner et al. 2018), such a study and a systematic review of these studies could not be reached in national literature. Therefore, in this study, it is aimed to make a systematic review of the effects of CBT-based interventions on family caregivers of people with dementia. The systematic review question that was created at the beginning of this review is "Is cognitive behavioral therapy interventions effective for family caregivers of people with dementia?"

Method

Researches published between 1990 and 2020 in EBSCHOHost (including Medline), Web of Science and Cochrane (including PubMed and Embase) databases were searched in order to review CBT-based interventions for family caregivers of people with dementia. The current study carried out a systematic review of literature in accodance with Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guideliness which used in reporting systematic reviews (Moher et al. 2009). Since a national study in this context could not be reached, searches were made in English and were conducted during March 2020 using the following search terms: "cognitive behavioral therapy" and "caregivers of people with dementia", "cognitive behavioral therapy" and "dementia caregivers" "cognitive behavioral therapy" and "caregivers of Alzheimer patients", and "cognitive behavioral therapy" and "Alzheimer's caregiver".

While examining the CBT-based interventions for family caregivers of people with dementia within the scope of searching, there was no limit on the way the intervention was applied (face-to-face, telephone and Internet), duration and frequency of sessions, and the number of participants. In addition, there was no restriction on the age of the participants, the gender distribution in the study, responsibilities related to caregiving of the caregivers, and duration of caregiving. Inclusion criteria; (1) the participants are caregivers and the family member of the people with dementia, (2) the intervention is based on CBT. Studies were excluded from the review if they were (1) comparison and consolidation of the elements of the CBT, (2) investigating the process of the intervention, not the outcome of the intervention, (3) case study, (4) review study, (5) no English, (6) no quantitative analysis.

Results

Study selection

As a result of the search process, a total of 819 studies were identified, EBSCHOHost (n=150), Web of Science (n=483) and Cochrane (n=186). When these studies were examined, it was determined that 461 studies were repeated. After duplicate studies were excluded, the remaining 358 studies were evaluated based on inclusion and exclusion criteria. 308 of 358 studies did not meet the inclusion and exclusion criteria. The full text of the remaining 50 studies were evaluated, 30 of the studies were not included in this article due to case study (n=3), review study (n=14), writing in languages other than English (n=5), comparison of the way the therapy was given (n=3), investigating the therapy process (n=4) and qualitative analysis (n=1). Twenty studies evaluated as full-text were included in the current review article. The PRISMA flow diagram of the study is given in Figure 1.

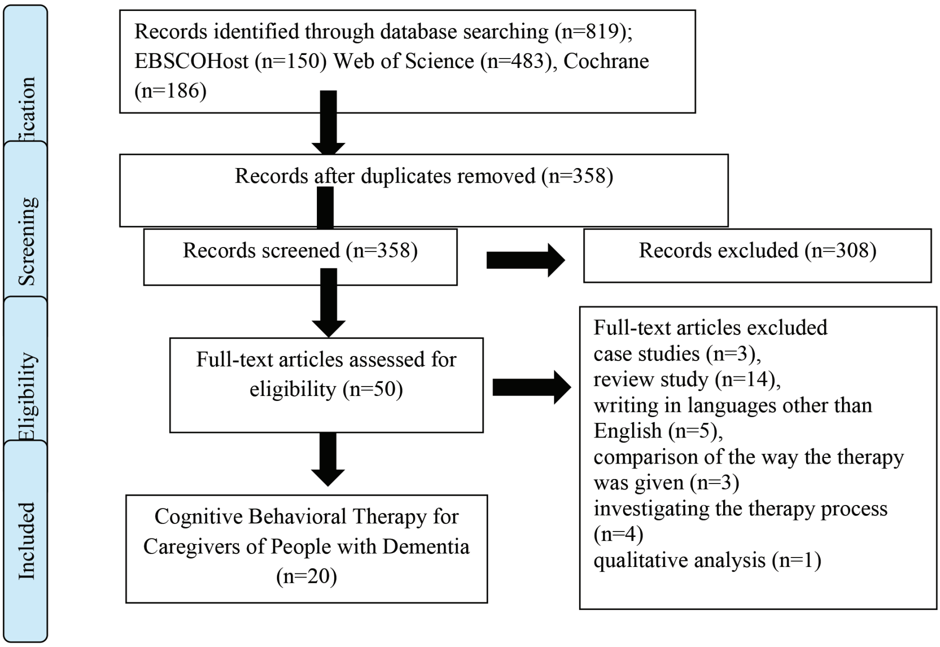

Figure 1. PRISMA akış diyagramı (Moher et al. 2009)

Study characteristics

In this section, information about 20 studies in this article will be given. Regarding where these studies are carried out, the type of dementia of the care receivers, the closeness of the caregivers to the people with dementia, the number of participants in the study, the ages and genders of the participants, the average care periods and the weekly hours for caregiving and whether there is a control group is presented in Table 1. In Table 2, interface mode (face-to-face, telephone and Internet), treatment paradigm (individual and group), schedule of sessions (number, frequency and duration), CBT techniques and interventions applied, evaluation time points, measurement methods and benefits of CBT is given. The numbers given as reference within the scope of this section (in the following paragraphs) are given in Table 1.

Country in which the data were collected

Considering from which country the data of the studies were collected, the data were collected from countries such as America (2, 5, 6, 7), Pakistan (3), United Kingdom (4),

Table 1. Characteristics of the studies and participants

Numbers in the results section	Study authors and year	Country	Type of Dementia	Relationship of caregivers of people with dementia	Number of participants
1	Aboulafia-Brakha et al. 2014	Brazil (Sao Paulo)	AL	Spouse, children	27
2	Akkerman and Ostwald 2004	USA (Teksas)	AL	NI	35
3	Ali and Bokharey 2015	Pakistan (Lahor)	AL	Spouse, children, daughter in law	8
4	Barnest and Markham 2018	UK	AL, VD and MT	Spouse, children	52
5	Gallagher-Thompson et al. 2007	USA (San Francisco)	Dementia	Spouse, daughter, and daughter in law	45
6	Glueckauf et al. 2007	USA (Florida)	AL and VD	Spouse, children, sister and niece	14
7	Gonyea, Lopez and Velasquez 2016	USA (Massachusetts)	AL	Spouse, daughter and others	67
8	Kwok et al. 2014	Hong Kong	Dementia	Spouse, children, daughter in law, son in law, grandchildren	26
9	Losada et al. 2011	Spain (Madrid)	AL and other type	Spouse, children, daughter in law, son in law, niece and others	157
10	Marquez-Gonzalez et al. 2007	Spain (Madrid)	Dementia	Spouse, son and other relatives	74
11	Meichsner et al. 2018	Germany (Jena)	AL, VD, FT and U	Spouse and children	37
12	Meichsner et al. 2019	Germany (Jena)	AL, VD, FT and Other Types/U	Spouse, children and others	273
13	Meichsner and Wilz 2018	Germany (Jena)	AL, VD, FT and Other Types/U	Spouse, children or other relatives	273
14	Pan and Chen 2019	China	AL, VD, SMMT <17	Spouse and others	112

Mean age/ standard deviation	Age Range	Distribution of gender	Type of control group	Mean duration of caregiving	Mean hours of caregiving for per week
CBTG: 59.42/6.67, EG: 55.07/ 10.68	NI	CBTG: 100% F, EG: 67% F	Comparison of CBTG and EG	CBTG: 2.92 years, EG 3.60 years	CBTG: 42, EG: 37.8
NI	NI	NI	Waitlist	NI	NI
52.38/ 15.54	40-74	37.5% M, 62.5% F	No	40 months	NI
67/12.9	30-89	23% M, 67% F	Discussion group taken only information	NI	NI
BMG:60.91/10.99 TSG: 57.83/13.38	NI	100% F	TSG	BMG 48.32 months, TSG 41.26 months	NI
60.46/12.21	NI	78.57 % F, 21.43% M	Control group given education and support (options to participate in intervention after study was completed)	5.50 years	46.14
54.6/3.1	NI	95.52 % F 4.47 % M	Psychıeducation control group	NI	84
NI	31- 60 and higher than 60	73.1% F, 26.9% M	No	NI	NI
IG: 60.60/11.52, CG: 59.38/12.58	IG: 35-58, CG: 33-84	IG 81.7% F, 18.3% M, CG 84% F, 16% M	Standart care (options to participate in intervention after study was completed)	IG 50.76 months, CG 60.80 months	IG: 80.71, CG: 70.07
CDTG: 58.1/13.9, WLCG: 55.4/15.9	CDTG: 24-83, WLCG: 18-85	CDTG: 82.4 % F, 17.6% M, WLCG: 77.5% F, 22.5% M	Waitlist	CDTG: 52.8, WLCG: 49 months	CDTG: 91, WLCG: 63.7
62.11/9.67	41-82	78.4% F, 21.6% M	Waitlist	4.5 years	NI
64.19/11.04	23-91	80.6% F, 19.4% M	Standard care	4.89 years	NI
64.20/11.04	23-91	80.6% F, 19.4% M	Written information about caregiving and dementia and 40 Euros	4.89 years	NI
62.7/10.9	NI	62.5% F, 37.5% M	Telephone interview asking daily questions for 5-10 minutes once in a month	67.3 months	119

Table 1. Continued

Numbers in the results section	Study authors and year	Country	Type of Dementia	Relationship of caregivers of people with dementia	Number of participants
15	Passoni et al. 2014	Italy (Milano)	AL	Spouse, children and sister	102
16	Töpfer and Wilz 2018	Germany (Jena)	AL, VD, FT and Other Types/U	Spouse, children and others	273
17	Wilz et al. 2017	Germany (Jena)	AL, VD and U	Spouse, relative from same generation, daughter, daughter in law, relative from younger generation	105
18	Wilz et al. 2018a	Germany (Jena)	AL, VD, FT and Other Types/U	Spouse, children and others	273
19	Wilz and Soellner 2016	Germany (Hildesheim)	AL, VD and Other Types	Spouse, children, daughter in law, son in law	191
20	Wilz et al. 2018b	Germany (Jena)	Half of them AL	Spouse, children	139

AL: Alzheimer's, BMG: Behavioral Management Group, CBTG: Cognitive Behavioral Therapy Group, CDTG: Changing Dysfunctional Thoughts Group, CG: Control Group, EG: Education Group, F: Female, FD: Frontotemporal Dementia, IG: Intervention Group, M: Male, MT: Mixed Type, NI: No Information, SHG: Self-Help Group, MMSE: Mini Mental State Examination, TSG: Telephone Support Group, U: Unknown, VS: Vasculer Dementia, WLCG: Waitlist Control Group

Germany (11, 12, 13, 16, 17, 18, 19, 20), China (14), Hong Kong (8), Italy (15), Brazil (1) and Spain (9, 10). In other words, CBT-based intervention studies on family caregivers of people with dementia were carried out in many different countries. This summary information is presented in Table 1.

Participants

In addition to the information about where the studies were carried out, the characteristics of the family caregivers of people with dementia and people with dementia were also examined. Within the scope of people with dementia, information about the type of dementia was also obtained. While 3 of the 20 studies did not specify the type of dementia (5, 8, 10), all of the remaining studies included care receivers who were diagnosed with Alzheimer's type. In addition to Alzheimer's type dementia, 10 of other studies included vascular dementia (4, 6, 11, 12, 13, 14, 16, 17, 18, 19), and 5 have frontotemporal dementia (11, 12, 13, 16, 18). In summary, studies were examined caregivers caring for people with different types of dementia.

Mean age/ standard deviation	Age Range	Distribution of gender	Type of control group	Mean duration of caregiving	Mean hours of caregiving for per week
CBTG: 58.9/12.9, SHG: 56.5/12.2, CG: 60.1/13.1	NI	78.43% F, 21.6% M	Self-help group and control group incuded only assessment	NI	NI
64.19/11.04	23-91	80.6% F, 19.4% M	Standard care	4.89 years	NI
61.40/9.41	NI	82.9% F, 17.1% M	Standard care	4.406 years	81.8% 7/24.
64.19/11.04	23-91	80.6% F, 19.4% M	Standard care	4.89 years	NI
62.01/9.33	NI	82.2% F, 17.8% M	Control group not taken any intervention and progressive muscle relaxation group for controlling attention	5.45 years	NI
63.91/11.47	23-85	80.6% F, 19.4% M	No	4.02 years	NI

Within the scope of the characteristics of the family caregivers of people with dementia, their relationship with the care receiver, their age, gender, duration of care and weekly hours of care were examined. When the relationship of family caregivers of people with dementia with people with dementia was examined; In 1 of 20 studies, information about the relationship between the family caregivers of people with dementia and people with dementia was not available (2), spouses included in the remaining studies, children in 18 studies (1, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12, 13, 15, 16, 17, 18, 19, 20), daugter in law in 6 studies (3, 5, 8, 9, 17, 19), son in law in 3 studies (8, 9, 19), sisters in 2 studies (6, 15), nephews in 2 studies (6, 9) and grandchildren in 1 study (8). When the average age is evaluated, the average age of the participants in the studies varies between 52.38 and 67, except for 2 studies (2, 8) where no information is provided. In addition to the ages of the participants, information about their gender was also examined, and 1 out of 20 studies did not provide information on gender distribution (2), while 19 of the 19 studies provided were more women, and even 100% of 1 study was women (5). In 15 of the 20 studies analyzed, information about the duration of care were given, and the mean duration of care ranged from 2.92 years to 5.6 years (1, 5, 6, 7, 9, 10, 11, 12, 13, 14, 16, 17, 18, 19, 20). In addition, 7 studies provide information on the average number

Table 2. CBT characteristics in the included studies

Study authors and year	Interface mode	Treatment paradigm	Schedule of Sessions (number/frequency/ duration)	CBT components
Aboulafia-Brakha et al. 2014	Face-to-face	Group (6-9 caregivers)	8/weekly/90 minutes	Psychoeducation, cognitive restructring, behavioral activation, behavioral management, reestablishing close relationship with care receiver by reviewing old relationship, expected grief and progressing of the disease, caregiving burden and identification of sign of stress and suggestions for better coping
Akkerman and Ostwald 2004	Face-to-face	Group (4-8 caregivers)	9/weekly /2 hours	Skill training and physical, cognitive and behavioral components of caregivers' anxiety
Ali and Bokharey 2015	Face-to-face	Individual	10/weekly or twice a week/45-60 minutes	Psychoeducation, cognitive restructring, relaxation exercises, coping skills, anger management, assertiveness training, self-management and self-soothing exercises, subjective burden management and physical health, sleep hygiene, time management skill, relapse prevention and social support services
Barnest and Markham 2018	Face-to-face	Individual	3/3 sessions within 8 week/1 hour	Communication and basic principles of CBT
Gallagher-Thompson et al. 2007	Face-to-face	Individual (at home)	6 modul (for every modul, one or more weeks are needed)/continue 4 months/ 90 minutes	Behavioral management, cognitive restructring, communication and activity planning
Glueckauf et al. 2007	Telephone	Group (7 sessions) + Individual(5 sessions)	12/ weekly/ First 6 sessions 45 minutes, 7th-11th sessions 1 hour	Overview of basic characteristics of dementia, relaxation education, effective thinking about challenging nature of caregiving, pleasant activity scheduling, assertiveness, problem solving and social support related to caregiving situation and family
Gonyea et al. 2016	Face-to-face	Group	5/weekly/90 minutes (After 3rd, 6th, 9th and 12th weeks group sessions, telephone interview was made.	ABC model of CBT (antecedent of behavior, behavior and consequence of behavior), activity planning, improving communication, relaxation exercises, problem solving and improving self efficacy
Kwok et al. 2014	Internet	Individual	9/ weekly /NI	Management of behavioral and psychological symptoms of people diagnosed with dementia (changing dysfunctional thoughts related to those symptoms, self-help strategies, effective and practical coping strategies and handling positive outcomes)
Losada et al. 2011	Face-to-face	Group (max 8 caregivers)	12/weekly/average of 1,5-2 hours	Cognitive restructuring, behavioral activation, asking help
Marquez-Gonzalez et al. 2007	Face-to-face	Group (max 8 caregivers)	8/ weekly /2 hours	Cognitive restructuring and coping skills (help-seeking and assertiveness, relaxation techniques and increasing pleasant activity)

Evaluation time points	Measurement methods	Benefits of CBT
BI and AI	PSS, ZBI, BDI, STAI, PFAQ, BEHAVE-AD and Saliva Samples	Level of cortisol and noropsychiatric symptoms of people diagnosed with Alzheimer's
BI, AI and follow up measurement (6 weeks after intervention for intervention group, 10 and 16 weeks after intervention for wait list control group)	BAI, HAM-A and Physiological Assessment	Anxiety
BI and AI	BAS, GHQ-28 and STAXI-2	Burden, Physical and Mental Health, Anger
BI and assessment within 12 weeks after intervention begins.	HADS, AC-QoL, CSES, GSE, CCS and TEI	Communication difficulties, feeling value given by care receiver, seeing care receiver compotent about communication
BI and AI	CESD, PSS, RMBPC, SES-R and SL-ASIA	Stress related caregiving, depressive symptoms
BI and 1 week after intervention ended	CAI, CSE, CESD, ISS, IFS, ICS and CSQ	Perceived self-efficacy, problem solving, satisfaction of intervention
BI, AI and follow up assessment 3 months after intervention	NPI, CESD, CSE-R and STAI-S	Noropsychiatric symptoms of people diagnosed with dementia and distress of caregiver of people with dementia about it, self-efficacy of caregiver and depressive symptoms
BI and 1 month after intervention	NPI and CSE-R	Behavioral and psychological symptoms of care receiver and distress of caregiver about it, caregiver self-efficacy in controlling upsetting thoughts
BI and AI	RMBPC, DTCQ, LTS and CESD	Dysfunctional thoughts, behavioral activation and depressive symptoms
BI and AI	CESD, DTCQ, MBPC and ATI	Depressive symptoms, dysfunctional thoughts and assessment of problematic behaviors

Table 2. Continued

Study authors and year	Interface mode	Treatment paradigm	Schedule of Sessions (number/frequency/ duration)	CBT components
Meichsner et al. 2018	Internet	Individual	8/All sessions completed within 8 to 20 weeks/NI	Psychoeducation, problem solving, changing dysfunctional cognitions, increasing support, coping with change, grief and loss, self-care and increasing activity, stress management and emotional regulation strategies
Meichsner et al. 2019	Telephone	Individual	12/first 4 sessions weekly, following 6 sessions biweekly, and last 2 sessions montly and all sessions completed within 6 months/50 minutes	Problem solving, psychoeducation, changing dysfunctional cognitions, increasing support for caregiving, coping with change, grief and loss, self-care, activity scheduling, stress management and emotional regulation strategies
Meichsner and Wilz 2018	Telephone	Individual	12/first 4 sessions weekly, following 6 sessions biweekly, and last 2 sessions montly and all sessions completed within 6 months/50 minutes	10 moduls focused on changing dysfunctional cognitions and coping with behavioral problems challenging part of caregiving. The most important modul is coping with change, grief and loss. In this modul, identification and expression of painful thoughts and emotions, management of painful emotions, acceptance of thoughts and emotions, identification and changing of dysfunctional cognitions, redefinition of relationships, activation of resources, adaptation of loss were handled.
Pan and Chen 2019	Face-to-face	Individual (at home)	5/montly/60 minutes (After every sessions, telephone assessment continued 20-30 minutes were made)	Evaluations of stresses, assessments and coping and education about them, skill management and relaxation.
Passoni et al. 2014	Face-to-face	Group (7-10 caregivers)	6/ biweekly/ 2 hours	Psychoeducation, restructring of thoughts, coping, problem solving
Töpfer and Wilz 2018	Telephone	Individual	12/first 4 sessions weekly, following 6 sessions biweekly, and last 2 sessions montly and all sessions completed within 6 months/50 minutes	Problem solving, psychoeducation, changing dysfunctional cognitions, increasing support in caregiving, coping with change, grief and loss, self-care, activity planning, stress management and emotional regulation strategies
Wilz et al. 2017	Telephone	Individual	7/first 4 sessions weekly, 5th and 6th sessions biweekly, after 1 month 7th session was done. All sessions completed within 3 months/60 minutes	Problem solving, rol playing, self-care activity, cognitive evaluation and reevaluation techniques, anger management, cognitive restructring, psychoeducation, handling of changing of roles and emotions about loss, coping with loss and change and redefining new roles

Evaluation time points	Measurement methods	Benefits of CBT
BI, AI, 5 months after BI assessment	CSQ, CESD, CGS and PRUQ	Well-being, coping with expected death of care receiver, psychosocial resource utilization
BI, AI and 6 months after intervention	WHOQOL-BREF	Quality of life, satisfaction with health condition, physical and psychological health
BI, AI and 6 months after intervention	CGS	Burden due to grief before loss
BI, AI and 2 months after intervention	CESD, SCSQ, ADLs and MMSE	Depressive symptoms and active coping
BI and 6 months after intervention	IADL, AD-R, DQ-R, STAI-X3 and CNA	Anxiety and need of caregiving
BI, AI and 6 months after intervention	PRUQ	Well-being, utilization more resource related to cope with daily hassles
BI and 2 years after intervention	CESD, GBB-24, WHOQOL-BREF and VAS	Emotional wee-being, health condition, bodily complaints and quality of life

Table 2. Continued

Study authors and year	Interface mode	Treatment paradigm	Schedule of Sessions (number/frequency/ duration)	CBT components
Wilz et al. 2018a	Telephone	Individual	12/ first 4 sessions weekly, following 6 sessions biweekly, last 2 sessions montly. All sessions completed within 6 months /50 minutes	Problem solving, psychoeducation, changing dysfunctional cognitions, increasing support for caregiving, coping with change, grief and loss, self-care, activity planning, stress management and emotional regulation strategies
Wilz and Soellner 2016	Telephone	Individual	7/first 4 sessions weekly, 5th and 6th sessions biweekly, after 1 month 7th session was done. All sessions completed within 3 months/60 minutes	Problem solving, coping with challenging behavior of people with dementia, increasing self-care, activity planning, creathing techniques, anger management, emotional regulation skills and coping, cognitive restructring, psychoeducation, coping with changing role, loss and grief
Wilz et al. 2018b	Telephone	Individual	12/ all sessions completed within 6 months /50 minutes	Problem solving, psychoeducation, changing dysfunctional thoughts, increasing support for caregiving, coping with change, grief and loss, self-care, activity planning, stress management and emotional regulation strategies

Note 1: BI: Befrore intervention, AI: After intervention

Note 2: AC-QoL: Adult Carers Quality of Life Scale, AD-R: The Anxiety and Depression Scale-Reduced Form, ADLs: Activities of Daily Living Scale, ATI: Assessment of Treatment Implementation, BAI: Beck Anxiety Inventory, BAS: Burden Assessment Scale, BDI: Beck Depression Inventory, BEHAVE-AD: Behavioral Pathology in Alzheimer's Disease, CAI: Caregiver Appraisal Inventory, CCS: The Communication Competence Scale, CESD: Center for Epidemiological Studies Depression Scale, CGS: The Caregiver Grief Scale, CNA: The Caregiver Need Assessment, CSE: The Caregiving Self-Efficacy Scale, CSE-R: Revised Scale for Caregiving Self-Efficacy, CSES: The Communication Self Efficacy Scale, CSQ: Client Satisfaction Questionnaire, DTCQ: Dysfunctional Thoughts about Caregiving Questionnaire, DQ-R: Depression Questionnaire-Reduced Form, GAS: Goal Attainment Scaling, GBB-24: Gießener Beschwerdebogen, GHQ-28: General Health Questionnaire-28, GSE: The General Self-Efficacy Scale, HADS: Hospital Anxiety and Depression Scale, HAM-A: Hamilton Anxiety Rating Scale, IADL: Instrumental Activities of Daily Living, ISS, IFS, ICS: Problem Change Measures, LTS: Leisure Time Satisfaction Scale, MBPC: Memory and Behavior Problems Checklist, MMSE: Mini Mental State Examination, NPI: Neuropsychiatric Inventory, PFAQ: Portable Functional Assessment Questionnaire, PRUQ: Psychosocial Resource Utilization Questionnaire, PSS: Perceived Stress Scale, RMBPC: Revised Memory and Behavior Problems Checklist, SCSQ: Simplified Coping Style Questionnaire, SES-R: Revised Self-Efficacy Scale, SL-ASIA: The Suinn-Lew Asian Self-Identity Acculturation Scale, STAI: State-Trait Anxiety Inventory, STAI-S: State Anxiety Inventory-State, STAI-X3: State Anxiety Inventory Reduced Form, TEI: The Therapeutic Engagement Index and Readiness, VAS: Visual Analog Scale, WHOQOL-BREF: World Health Organization Quality of Life-BREF, ZBI: Zarit Burden Interview

Evaluation time points	Measurement methods	Benefits of CBT
BI, AI and 6 months after intervention	CESD, GBB-24, VAS and BEHAVE-AD	Emotional well-being, depression, symptoms of physical health, coping with caregiving and behaviors of care receiver
BI, AI and 6 months after intervention	CESD, GBB-24 and VAS	Well-being, bodily complaints, perceived health status, depressive symptoms
In the first and second sessions, goals were set. After intervention, therapist and participant evaluated whether participants attain goals or not.	GAS and adherence to treatment and application of treatment were assessed.	Attain personal goals, adherence to treatment and application of treatment

of hours of care per week. It was concluded that at least 37.8 hours of care is provided per week in the studies that are informed, and those who provide the most care provide 7/24 care (1, 6, 7, 9, 10, 14, 17). Characteristics of participants are given in Table 1. As a result, it is seen that a lot of demographic information were taken from family caregivers of people with dementia.

Characteristics of CBT applied in studies

In addition to demographic evaluations, the number of participants in the studies, the control groups and the ways in which interventions were applied were also examined. While the number of participants in the studies ranged from 8 to 273, 3 of the 20 studies did not have a control group (3, 8, 20). In one study, the education group and the CBT group were compared (1). Apart from these studies, standard care (9, 12, 16, 17, 18), the waiting list control group (2, 10, 12), the psychoeducation group (7), only discussion group (4), telephone interview group (14) progressive muscle relaxation group to control attention (19), training and support group (6), group providing written information about caregiving and dementia (13), self-help group (15) and a telephone support group (5) took place as a control group. When the application forms of the studies included in the review were evaluated, 10 of 20 CBT-based intervention were face-to-face (1, 2, 3, 4, 5, 7, 9, 10, 14, 15), 8 of them were telephone based (6, 12, 13, 16, 17, 18, 19, 20), and 2 of them were carried out via Internet (8, 11). The studies were applied both in groups and individually. While 4 of the face-to-face studies were performed individually (3, 4, 5, 14) and 6 of them were group (1, 2, 7, 9, 10, 15), 2 of the face-to-face individual studies were carried out in the houses of the caregivers (5, 14). In only 1 of the studies carried out via telephone, both individual and group interviews were made (6). Internet intervention were made individually (8, 11). It is seen that group interventions involved four to ten individuals in each group (1, 2, 6, 7, 9, 10, 15). In summary, as the number of participants varies, there were also many different control groups in the studies. In addition, CBT-based interventions can be applied individually and as a group, face to face via telephone and internet, for family caregivers of people with dementia.

When the schedule of sessions of all the studies handled in this study were evaluated, it was noteworthy that there were minimum of 3 sessions and maximum of 12 sessions (eg, 4, 9). The sessions were performed once a week, biweekly and once a month. Although the detailed contents of CBT varied, the main contents included psychoeducation, cognitive restructuring, relaxation exercises, problem solving, anger management, assertiveness training, activity planning, communication, coping with change, grief and loss, stress management and coping skills were frequently handled (eg, 2, 5, 15, 20). In other words, as the number of sessions differs in the studies, characteristics of CBT may also differ.

Measurement of CBT outcomes

In addition to the schedule of sessions and interventions applied, evaluation time points in 20 studies were examined in this review study. In 10 of 20 studies, measurements were taken only before and after the intervention (1, 3, 4, 5, 6, 8, 9, 10, 15, 20). In one study, measurements were taken before the intervention and 2 years after the intervention ended (17). Follow-up assessments were performed in the remaining 9 studies (2, 7, 11, 12, 13, 14, 16, 18, 19). The evaluated outcomes included anxiety (1, 2, 4, 7, 15), depression (1, 4, 5, 6, 7, 9, 10, 11, 14, 15, 17, 18, 19), stress (1, 5), burden of care (1, 3), general health, anger (3), bodily complaints (17, 18, 19), coping (14), quality of life (4, 12, 17), self-efficacy (4, 5, 6, 7, 8), communication competence and difficulty (4), daily life activities (14, 15), caregiver evaluations, problem situations (6), achievement of goals (20), psychological resource use (11, 16), grief (11, 13), caregiver's needs (15), functionality (1), dysfunctional thoughts (9, 10), free time satisfaction (9), self-identity culture (5), neuropsychiatric symptoms of the people with dementia (7, 8), the cognitive functions of the care receiver (14), the behavioral symptoms of dementia (1, 18), the memory and behavioral problems of people with dementia (5, 9, 10), therapeutic involvement (4), treatment satisfaction (6, 11) and treatment evaluation (10) were measured. Table 2 gives information about which inventories were used when making these measurements. As a result, evaluations were made regarding the caregiver, care receiver and the communication between them and many inventories were used.

Benefits of CBT

When evaluating the variables of CBT applied in the studies examined, CBT improved the following conditions in physical and mental / psychological health (3, 12, 18), health status (12, 17, 19), cortisol level (1), bodily complaints (17, 19), anxiety (2, 15), depressive symptoms (5, 7, 9, 10, 14, 18, 19), anger (3), stress associated with caregiving (5), need for care (15), burden of care (3), burden due to grief before loss (13), self-efficacy (6, 7, 8), quality of life (12, 17), well-being (11, 16, 17, 18, 19), coping (11, 14, 18), dysfunctional thoughts (9, 10), behavioral activation (9), problem solving (6), resource use (11, 16), achieving personal goals (20), neuropsychiatric symptoms of care receiver (1, 7, 8, 18), caregivers' distress with neuropsychiatric symptoms (7, 8, 10),communication difficulties, the value given by the person they care for, competence of care receiver in terms of communication (4), intervention satisfaction (6), compliance with the treatment and the application of the treatment (20). In parallel with the assessments made, it is seen that CBT interventions have positive contributions to family caregivers of people with dementia, people with dementia received care, and communication between them.

Discussion

The aim of this study is a systematic review of CBT-based interventions applied to family caregivers of people with dementia. In order to achieve this aim, EBSCHOHost (including Medline), Web of Science and Cochrane (including PubMed and Embase) databases were searched for studies conducted between 1990-2020, and the findings have been reviewed in accordance with the PRISMA Statement. As a result of this review, characteristics and findings of 20 studies that were found to comply with inclusion and exclusion criteria were reported.

Although the prevalence of dementia varies from region to region, dementia is seen globally (WHO 2015). For this reason, dementia is all over the world, wherever there are people with dementia, there are certainly caregivers. Therefore, it is seen that the studies handled in this study were carried out in many different countries. In other words, there are CBT interventions for caregivers of people with dementia with very different cultural characteristics in parallel with prevalence.

In addition to the country in which the data were collected, type of dementia were also evaluated. Dementia is the general name of the disorders that cause deterioration in individuals' memories, thoughts, behaviors and their ability to continue their daily lives (WHO 2019). There are different types of dementia, and in a study examining the prevalence of these types, it was concluded that the most common diagnosis was Alzheimer's, followed by vascular dementia and other related conditions (Plassman et al. 2007). The studies included in this study were in parallel with this prevalence. While caregivers of people with Alzheimer's were included mostly, it is followed by vascular dementia and frontotemporal dementia. In other words, different types of dementia were covered in these studies.

There are consistent findings in the literature that greater proportion of family caregivers of people with dementia are women (eg, Xiong et al. 2018). In addition, it was concluded that family caregivers of people with dementia are mostly wives and daughters (Kwon et al. 2017). The results of the studies included in this study were in line with these findings. Since family caregivers of people with dementia are often women, there are more women in intervention studies for caregivers. In addition, it is stated that the lives of women caregivers are more negatively affected by the caregiving process (Pillemer et al. 2018). Perhaps this negative impact makes women caregivers more open to seeking help and may be more willing to intervene and thus participate in such intervention studies. When evaluated in general, women have more positive attitudes towards receiving psychological support (Koydemir-Özden 2010). It is thought that this difference and more women in caregiving may also lead to more women in intervention studies. After the gender distribution, the ages of the family caregivers of people with dementia were evaluated. Considering that the family caregivers of people with dementia are mostly spouses and children (Fauth et al. 2012), it is inevitable that the age range in studies is wide. In fact, in a study, when the information of grandchildren as a family caregivers of people with dementia is evaluated (Kwok et al. 2014), it is predicted that this age range may be even wider. As a result, although there is not a very equal distribution in terms of gender in caregiving, there is a difference in terms of ages of caregivers.

In addition, there is a control group in 17 of the studies. It is remarkable that certain interventions are also made for the participants in the control groups in the studies. Family caregivers of people with dementia are very in need of psychological intervention (Soner and Aykut 2017). While waiting list formed the control group in some studies (eg Akkerman and Ostwald 2004, Meichsner et al. 2018), a group of studies also provided the participants in the control group the option to participate in the intervention after the study was completed (eg, Glueckauf et al. 2007, Losada et al. 2011). This creates a very advantageous situation for a group that needs psychological intervention so much.

Giving care to people with dementia brings many different services (Alzheimer's Association 2004). Family caregivers of people with dementia spend a lot of time to provide these services (Schulz et al. 2003). These situations may hinder family caregivers of people with dementia (Altuntaş and Koç 2015), as well as making it difficult for them to participate in a therapy (Czaja and Rubert 2002). For this reason, it might be difficult to reach caregivers and continue and terminate a long-term intervention study. This causes work to be carried out with fewer participants. As a matter of fact, in the studies examined, it is striking that there is an intervention with 8 participants (Ali and Bokharey 2015). It is difficult for family caregivers of people with dementia to participate in therapy (Czaja and Rubert 2002) directed the researchers to do therapy in different ways. As well as face-to-face therapy, intervention studies were applied via telephone and Internet (eg, Glueckauf et al. 2007, Kwok et al. 2014, Gonyea et al. 2016). As can be seen in the studies dealt with, the implementation of interventions in this way reduces the possibility of abandoning the intervention, and most importantly, it is instrumental in providing psychological assistance to a group who needs such intervention. In addition, it is observed that there are also interventions carried out in the caregivers' homes to increase participation even if the studies are carried out face to face (Gallagher-Thompson et al. 2007, Pan and Chen 2019). In other words, steps have been taken to facilitate participation for family caregivers of people with dementia who has difficulty in participating in therapy.

When the studies included in this review are evaluated, some suggestions were made for future research. In the interventions, it was seen that measurement is taken before and after the intervention. Follow-up studies were in the minority and it was seen that a follow-up measurement of at most 2 years is taken. However, it is known that caregiving is a long process. It was stated that 71% of family caregivers of people with dementia have been caring for more than 1 year and 32% have been caring for more than 5 years (Alzheimer's Association 2004). For this reason, in future studies, carrying out studies on how long the gains continue and at what point it has started to be disrupted will contribute to the family caregivers of people with dementia living psychologically healthier. If these situations are determined in future interventions, the intervention studies will be shaped according to these situations and the benefits of intervention for family caregivers of people with dementia will continue for a longer period.

Researchers also have difficulties in terms of participants because family caregivers of people with dementia have difficulty in participating in the interventions. In the studies conducted, it was seen that spouses, children and other family members were evaluated together. However, studies showed that the causes of stress that spouses and children experience due to caregiving were different. While the sources of stress for spouses were physical and economic problems associated with being older and being older, the sources of stress for adult children were conflicting responsibilities (Oyebode 2003). In future studies, studies that can reach more participants may create an intervention by separating family caregivers of people with dementia according to their relationships. For example, a study for adult children might address role conflict in more depth. The realization of the intervention in this way can also benefit the participants and future individuals more and shed light on future studies. In addition, in these studies, information was obtained about the duration of caregiving and how much care they provide per week. It is stated that family caregivers of people with dementia living with people with dementia were more negatively affected by the caregiving (Mahoney et al. 2005). For this reason, it will be useful to check the duration of caregiving and how much they care per week.

Concepts such as depression, anxiety, and stress were evaluated in the studies covered in this study (eg, Akkerman and Ostwald 2004, Gallagher-Thompson et al. 2007), but in one study, resource utilization was handled different from other studies (Töpfer and Wilz 2018). Although caregiving was associated with negative consequences, it was also possible to provide positive gains for caregivers (Roth et al. 2015). It is important to evaluate caregiving in this sense and to reveal the strengths of individuals.

In addition, a study in the national literature related to CBT for caregivers of people with dementia could not be reached. It is important to develop and implement interventions in such a needed sample. In addition, it is noteworthy that there are steps to be taken in terms of interventions, as well as scales to evaluate caregivers. In this sense, in future studies, both the intervention and the scales for caregivers should be developed or adapted.

Within the scope of this study, studies related to a certain time period were searched with specific keywords, databases and based on inclusion and exclusion criteria. Publications that were not included in these reviews, for example, outside the time period examined, not in English, could not be reached with related keywords, were not published in refereed journals, case studies or unpublished publications might be missed. This limitation and limitations of related databases constitute the limitations of the study.

Conclusion

Consequently, within the scope of this study, CBT-based interventions that were conducted for family caregivers of people with dementia between 1990 and 2020 were reviewed according to PRISMA Statement. It was expected that there will be more individuals who will be diagnosed with dementia in the coming years, which will increase the importance of caregiving. Giving care can be challenging for individuals and caregivers need psychological support. Although CBT-based interventions were applied in different ways, in different periods, with different techniques, and handled with different outcome variables, it is seen that CBT has important benefits for caregivers. However, more studies are needed for a group that needs psychological help. In recent years, many attempts have been made to support the participation of participants. These initiatives should be supported to continue increasingly in the following years. In the literature, it was seen that nterventions did not evaluated separately according to type of dementia, or relationships between caregivers and people with dementia. Perhaps, as the participation is increased, separate groups will emerge among the caregivers, and practices will be carried out according to those groups. In addition, long-term interviews and assessments are needed as caregiving for dementia involve a long process. In the national literature, it is seen that intervention and scale studies are limited for such a group that is needed, it is thought that conducting such studies will be a guide for further studies.

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