

RESEARCH ARTICLE

Methodologies That Improve Self-Compassion in Dementia Family Caregivers: A Systematic Review

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Abstract

This review aimed to identify methodologies that improve self-compassion among family caregivers with dementia using a systematic review approach and to obtain suggestions for building future support. This systematic review was conducted in accordance with the Minds Clinical Practice Guideline Development Manual 2020, ver. 3. Medical Journal Web, MEDLINE/PubMed, EMBASE, and Cochrane Library were searched. Three articles met the eligibility criteria for primary and secondary screening; they were reviewed by two investigators to evaluate the intervention program in terms of effectiveness and risk of bias. Although the intervention program, duration, and time differed across studies, all three studies found improved self-compassion after the intervention, suggesting that mindfulness-centered interventions are useful for improving self-compassion among family caregivers of people with dementia. However, due to the paucity of previous studies and differences in intervention content among the literature, it is not possible to say that these programs have been sufficiently validated, and that conducting randomized controlled trials would be beneficial.

Keywords: Family Caregivers, Patients with Dementia, Self-Compassion, Systematic Review.

1. Introduction

Dementia is the most common reason for people to need caregiving in Japan,¹ and as approximately 60% of patients with dementia wishing to remain at home,² there is concern about the increasing burden of caregiving on family caregivers. Building support that will reduce the burden on both those with dementia and their family caregivers is therefore essential.

Previous studies have indicated that when caregivers objectively look at the care they provide, they are concerned that the care they provide is inadequate, causing their sense of competence to decrease.³ It has also been shown that caregivers experience psychological problems⁴⁻⁶ for many reasons, including not only the core symptoms of dementia (memory impairment), but also psychological symptoms, such as depression, anxiety, agitation, and hallucinations, and behavioral symptoms, such as wandering, violent

outbursts, and violent behavior.⁷ Reports have also shown that self-efficacy and self-esteem need to be improved to improve depression symptoms.⁸

Against this background, improving self-compassion is considered important in cognitive behavioral therapy, which is believed to be useful in improving self-efficacy and self-esteem.⁹⁻¹⁰ Self-compassion involves demonstrating compassion towards oneself rather than engaging in self-critical behaviors.¹¹⁻¹² It has been pointed out that immersing oneself in self-criticism when an action does not lead to satisfactory results does not lead to positive cognition and behavior,¹³ and that an effective way to address self-criticism is to understand it, express compassion toward oneself, and replace self-criticism with gentler ways of coping.¹¹⁻¹² Previous studies have indicated that people with higher self-compassion have fewer negative emotions, are less likely to experience catastrophic cognitions,¹⁴ depression, anxiety,¹⁵ and

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have lower stress,¹⁶⁻¹⁷ therefore, self-compassion improves mental and psychological health.¹⁸ As the burden on family members of providing care for persons with dementia, it is important to build support for improving self-compassion, which can lead to an increase in self-efficacy and self-esteem and a reduction in psychological problems, such as depression, by being compassionate in the face of self-criticism rather than being critical of their caregiving, which leads to a decreased sense of competence.

However, research in this field is still in its early stages, and methodologies to improve self-compassion among family caregivers of patients with dementia have not yet been sufficiently verified. Therefore, this study conducted a systematic review of randomized controlled trials focusing on the self-compassion of caregivers for patients with dementia with the goal of providing suggestions that can build support for family caregivers with dementia.

2. Materials and Methods

This systematic review was conducted in accordance with the Minds Practice Guidelines Development Manual 2020 ver. 3.0.¹⁹

2.1 Clinical Question (CQ) Formation and Literature Selection Criteria

We asked the question “What methodologies are available to improve self-compassion among family caregivers of patients with dementia?”

2.1.1 Literature Search and Selection

A comprehensive literature search was conducted using the Central Journal of Medicine Web, PubMed/MEDLINE, EMBASE, and the Cochrane Library. The search terms used were “dementia,” “family caregivers,” and “self-compassion.” Only intervention studies focusing on the self-compassion of family caregivers for those with dementia were included in the search, and no other search conditions were set in order to conduct an exhaustive search. The search was last conducted on July 1, 2022. After the literature was extracted using the search terms and conditions, we excluded studies that (1) did not focus on family caregivers for those with dementia, (2) did not focus on self-compassion, (3) were not intervention studies, and (4) were reviews of existing literature. To conduct a comprehensive review of methodologies that can improve self-compassion among family caregivers of people with dementia, we also hand-searched literature that was judged eligible for inclusion.

The literature selected after this search was subjected

to a primary screening by two independent researchers. Articles that, based on the title and abstract, did not meet the clinical questions of the study, and those with similar themes and researchers’ names were considered duplicates and were excluded from the review. In the secondary screening, two researchers independently read the full text of the articles, selected those that met the selection criteria, and compared their results. If the two researchers disagreed, a third researcher’s opinion was obtained to determine whether the article was to be included. Only randomized controlled trials were selected for inclusion.

2.2 Literature Search Results

Figure 1 shows the results of the literature search.

A total of 72 articles were retrieved from the Central Journal of Medicine Web, 446 from PubMed, 180 from MEDLINE, 15 from EMBASE, and 10 from Cochrane. Duplicate references and references that met the exclusion criteria established for this study were deleted. Finally, three articles that met the eligibility criteria among the researchers were included in the analysis.

2.2.1 Extraction of Data

Selection of References

After excluding studies that were inconsistent with the eligibility criteria or different from the purpose of this study from the search results, the target studies were selected, and information was extracted by the researchers.

Setting of PICOS

PRISMA2020²⁰⁻²¹ is a revised version of the QUOROM statement²², which is a guideline for systematic reporting of randomized controlled trials that was published in 1999. PRISMA2020 consists of a 27-item checklist, and PICOS was established in accordance with it. The aim of this study was to evaluate the bias in the literature and the usefulness of the program for improving the self-compassion of family caregivers of those with dementia (C). The study design was a randomized controlled trial and a controlled trial. The study design of the literature included in this study is a randomized controlled trial (S), and no control group condition was established.

Assessment of Risk of Bias in the Literature

One outcome of this study was an assessment of bias in the target literature. This assessment followed the method recommended by the Cochrane Handbook for Systematic Reviews of Interventions²³ and a revised

tool (RoB 2)²⁴ was used to assess the risk of bias in randomized trials. We examined: (1) bias arising from the randomization process, (2) bias due to deviations from intended interventions, (3) bias due to missing outcome data, (4) bias in outcome measurements, and (5) bias in the selection of reported outcomes. In each of the five evaluation domains, bias evaluation was

conducted at three levels: low risk, some concerns, and high risk of bias. The five evaluation domains were combined to evaluate the overall bias. Each of the five evaluation domains consists of multiple signaling questions, and each question can be answered with (1) yes, (2) probably yes, (3) probably no, (4) no, and (5) no information.

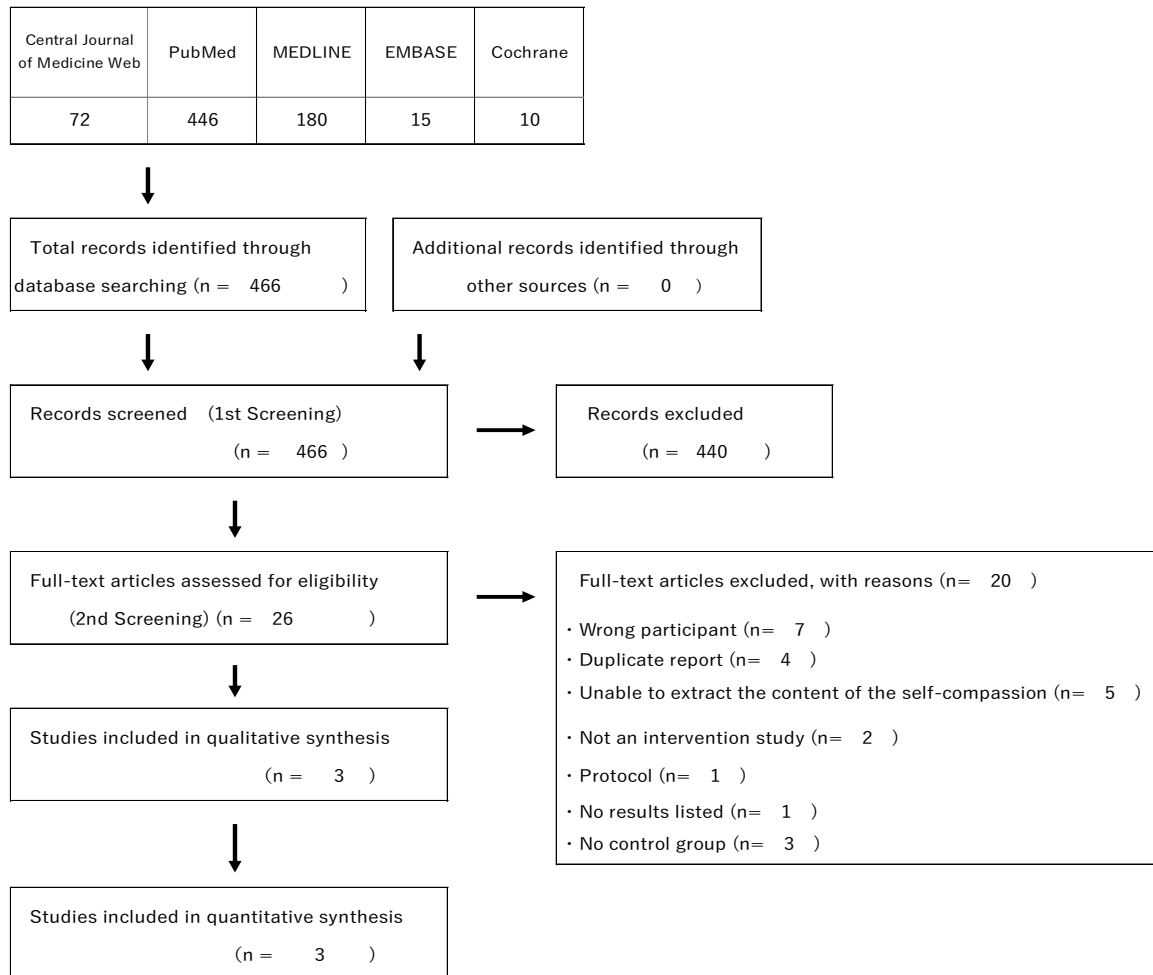


Figure 1. Literature Search Flowchart

Evaluation and Review Method of Literature

The two study authors reviewed the eligibility criteria and risk of bias for the selected studies. Discussions were held between them until consensus was reached, and the final studies were determined. If consensus could not be reached between the two researchers, a third researcher was asked for input.

3. Results

3.1 Self-compatibility of Family Caregivers with Dementia

3.1.1 Participant Selection, Allocation, and Dropout Rate

Table 1 lists the participant selection method, allocation, and dropout rates for each included study. The recruitment of the participants has been clearly

described in all three studies.²⁵⁻²⁷ The randomization of participant assignments to groups was also described in all references, but there was no clear description of how the participants were blinded. Only one study (no. 3) stated that the assessors were blinded. The eligibility criteria for participant selection were clearly identified in all references, but they were not standardized, and examining participants’ mental status prior to intervention was among the eligibility or exclusion criteria. Studies 2 and 3 mentioned the dropout rate, and it was low in both studies.

3.1.2 Effectiveness of the program in improving self-compassion of family caregivers with dementia

Table 2 presents the details of each study’s intervention program and its effects on improving self-compassion in family caregivers of individuals with dementia.

Although program names and content differed across the studies, all focused on mindfulness. Existing cognitive behavioral therapy programs consisted of 16 sessions, 45 minutes per session,²⁸ and mindfulness training programs, such as MBSR, consisted of 8 sessions, 150 minutes per session, along with a 360-minute long silent retreat.²⁹ The number of sessions ranged from 4 to 24 in the

literature examined for this review, and the duration of sessions ranged from 75 to 120 minutes. None of the existing studies explicitly described a silent retreat. Despite the differences in session structures among the included articles, all mindfulness-centered programs contributed to improved self-compassion among family caregivers of people with dementia.

Table 1. Subject selection, allocation, and dropout rates

No	author, year of publication, country	recruit	subjects	allocation method, allocated subjects, blinding	inclusion criteria, exclusion criteria	number of subjects, number of dropouts, dropout rate
1	Felipe. A. et al... 2022. USA	snowball sampling (facebook advertisements, direct mail, phone calls, caregivers of known dementia patients at UCSF)	46 caregivers ● Intervention group: 24 ● Control group (support group): 22 [Age] ● Intervention group: 61.0±8.4 ● Control group: 66.1±9.8	randomized online site (random.org), NA, study hypotheses were blinded, but not for groups, and participants were informed to expect both interventions to be useful	[inclusion criteria] ① be the primary family caregiver of a person with dementia, ② be at least 40 years of age, ③ be proficient in written and spoken English [exclusion criteria] ① have a primary psychiatric disorder other than unipolar depression, ② have an unstable medical condition or scheduled surgery that interferes with participation, ③ intend to cause violence or harm to a relative with dementia, ④ report to adult protective services, ⑤ have a cognitive impairment, ⑥ meditate/image practice at least twice a week.	24, NA, NA
2	Zarei. S., et al... 2022. Canada	snowball sampling (another project participant, dementia clinic, brochures and flyers, word of mouth)	24 caregivers ● Intervention group: 12 ● Control group: 12 [Age] ● Intervention group: unknown due to dropouts ● Control group: 63±15	randomized online site (graphpad.com/quickcalcs /index.cfm), NA, NA	[inclusion criteria] ① Family members of a medically diagnosed person with dementia, ② Can read and write English, ③ Have access to the Internet, ④ Are familiar with basic use of a computer or tablet (can check/send email, download files), ⑤ Score 3 or higher on a single-item measure of self-perceived stress, ⑥ not engage in caregiver support programs, psychosomatic programs, or psychotherapy until completion of training and follow-up evaluation, ⑦ have time to participate in an 8-week intervention program, ⑧ have no active self-harm or suicidal ideation, ⑨ No recent psychiatric diagnosis (major depression, anxiety, psychosis, or bipolar disorder), ⑩ No active substance abuse, ⑪ No initiation of new psychotropic medications within 3 months prior to study participation, and ⑫ No participation in a formal, professionally led meditation, yoga, or tai chi program within the past year. ※The following scale will be used in advance to determine eligibility ① a single-question measure of self-perceived stress ② Neuropsychiatric Inventory Questionnaire (NPI-Q) [exclusion criteria] NA	14, 2, 14.3 [Reasons for dropping out] Time constraints Want to spend more time on care
3	Danucalov Marcelo. A.D., et al... 2015. Brazil	radio, newspaper advertisements, the Alzheimer's Association of Brazil	46 caregivers ● Intervention group: 25 ● Control group: 21 [Age] ● Intervention group: 55.5±8.1 ● Control group: 53.4±8.2	subject takes one piece of paper from a box containing two types of paper labeled intervention or control group, evaluator is blinded	[inclusion criteria] ① 18 years of age or older, ② Completion of primary education or higher, ③ Stress resistance level or higher according to Lipp's Inventory of Stress Symptoms for adults [exclusion criteria] ① patients with asthma or chronic obstructive pulmonary disease, ② alcohol use (>5 drinks per week) or drugs of abuse, ③ Cushing's syndrome, ④ treatment with topical medications, nasal spray, or any form of steroid within the past 30 days, ⑤ practice of yoga, meditation, or similar techniques Person. ※Psychostimulants are permitted if they were started prior to the experiment and continued at the same dose during the experiment.	53, 7, 13.2 [Reason for dropping out] Due to duties as a caregiver Lack of time to participate in research

Table 2. Programs to improve self-compassion among family caregivers with dementia

No	Author, year of publication, country	therapists (number)	program, session duration, number of sessions, session duration (number of sessions), presence of retreats	session content	evaluation scale	results	control group	itt analysis
1	Felipe. A. et al... 2022. USA	NA	MIT (Mentalizing Imagery Therapy), 4, 4, 2, not setting ※Optional "refresher" sessions at 1 and 2 months after the end of the intervention	①Low-impact stretching and breathing meditation (mindfulness) ②Different specific guided imagery exercises (weekly) ※Designed to draw attention to different aspects (self - others, automatic control, internal - external, emotional - cognitive) and to situate the caregiver in connection with the social and ecological context	Self Compassion Scale (SCS)	【after intervention (pre-intervention comparison)】 ●Intervention : 3.7 [1.0, 6.3] ●Control : 2.0 [-0.7, 4.6], p =.007 【after 4 weeks】 ●Intervention : 4.1 [1.9, 6.3] ●Control : 3.5 [1.3, 5.7], p =.02	facilitated discussion focused on challenges faced by each caregiver and brief psychoeducation related to caregiving prior to implementation (approximately 20 minutes)	+
2	Zarei. S. et al... 2022. Canada	Clinician (1) (specialist physicians attending MCT)	Tele-MBCT (live online mindfulness-based cognitive therapy), 8, 8, 2, not setting ※Up to 2 sessions may be missed. The content of the missed sessions will be practiced daily according to the handouts provided and a 15-minute check-in session with the instructor prior to the next session	Training in mindfulness concepts and techniques (mindful eating, body scan, zazen, breathing, mindful walking, mindful movement, etc.) ※After each session, specific mindfulness exercises are practiced and recorded in a practice journal ※Allow 30-45 minutes per day to practice with the CD (guided meditations) and materials provided	Self Compassion Scale (SCS)	●Intervention : pre 2.57±0.62, post 2.85±0.73, follow 3.17±0.96 t(11) = -2.43, p= 0.03 ●Control : pre 3.10±0.64, post 2.94±0.73, follow 2.97±0.76 t(11) = 1.03, p= 0.32	Normal caregiving lifestyle	+
3	Danucalov Marcelo. A.D. et al... 2015. Brazil	NA	YCMP (yoga and compassion meditation program) , 8, 24, 1,25, not setting ※One session each week will be conducted in person and two sessions will be conducted on DVD	①Yoga poses -asana (25 minutes, holding each pose for an average of 1 minute 30 seconds) Sukhasana, Vajrasana, Yoga-Mudra, Paschimotanasana, Ardha-Matsyendrasana, Shavasana, Naukasana, Bhujangasana, Artha-Shalabhasana, Chakrasana, Vrikshasana and Sarvangasana ②Breathing Exercises - pranayama (25 minutes, holding each pranayama for an average of 3 minutes) Adhama Pranama, Bastrika, Ujjayi, Suryabhedana, Chandrabhedana, Nadisodhana and Kapallabhat ③Meditation practice - mindfulness meditation (about 12 minutes 30 seconds)	Self Compassion Scale (SCS)	【Self-kindness】 ●Intervention : pre 3.2±1.0, post 3.5±0.8, p<0.05, p=0.99, p<0.05 ●Control : pre 3.4±1.0, post 3.4±0.9, 7.2, <0.001, 4.7 【Common humanity】 ●Intervention : pre 3.4±0.9, post 3.7±0.7, p=0.10, p=0.40, p=0.19 ●Control : pre 3.3±0.8, post 3.4±0.9, 2.8, 0.7, 1.8 【Mindfulness】 ●Intervention : pre 3.2±0.8, post 3.6±0.8, p<0.01, p=0.62, p=0.10 ●Control : pre 3.2±0.9, post 3.3±0.8, 7.9, 0.3, 2.8	No treatment group	NA

3.2 Bias Risk Assessment of Target Literature

Table 3 presents the bias risk assessment of the three included studies.

Table 3. Bias Risk Assessment

No	Randomization process	Deviations from intended interventions	Missing outcome data	Measurement of the outcome	Selection of the reported result	Overall Bias
1	Low	High	Low	Low	Low	High
2	Low	Some concerns	Low	Low	Low	Some concerns
3	Low	Low	Low	Low	Low	Low

3.2.1 Bias Arising from the Randomization Process

Studies 1 and 2 used an online site to randomize their order of allocation while study 3 used a box with two types of paper, one for the intervention group and the other for the control group. In terms of concealment, none of the studies clearly described the recruitment of participants, allocation, or allocation order of interventions. Baseline imbalances reflecting problems with randomization were not found in any of the included studies.

3.2.2 Bias Due to Deviation from the Intended Intervention

In study 2, the patients were blinded to the group to which they were assigned. In study 3, the assessor was blinded to the group to which the patient was assigned. No deviations from the intended interventions were observed in any of the included studies. Studies 1 and 2 performed appropriate analyses to estimate the effect of adherence to the intervention. Study 3 did not provide an appropriate analysis, but there was no

indication that this could have seriously affected the outcomes of the study.

3.2.3 Bias Due to Missing Outcome Data

Outcome data for randomized participants were available for all included studies.

3.2.4 Bias in Outcome Measurement

The methods used to measure outcomes were appropriate in all the included studies. The methods used to measure outcomes did not differ between the groups in any of the included studies. The outcome assessors were unlikely to have been aware of which intervention the participants received.

3.2.5 Bias in Selection of Reported Outcomes

None of the studies we examined had more than one outcome measure or used more than one method to conduct data analysis.

3.3 Overall Evaluation

After reviewing the signaling questions for each assessment domain and assessing the risk of bias for each of the five assessment domains, study 3 was found to have low risk of bias, study 2 to have some concerns, and study 1 had a high risk of bias. Even given the high risk of bias, the researchers for this review determined that the potential bias did not have a significant impact on outcomes, and all three studies were therefore adopted as a review of methodologies that could improve self-compassion among family caregivers of those with dementia.

4. Discussion

4.1 Usefulness of Intervention Program for Family Caregivers with Dementia

4.1.1 Dropout Rate of Subjects

Studies 2 and 3 had clear descriptions of dropout rates, and each study had a low dropout rate. Considering the low dropout rate, the mindfulness-centered intervention program was considered easy for family caregivers with dementia to practice. In Study 2, the program had several characteristics: mindfulness exercises were practiced after each session and were written about in a logbook; CDs for practice were distributed; up to two absences were allowed; and follow-up for a missed session was conducted before the next session. In Study 3, there were two weekly DVD sessions in addition to the weekly face-to-face sessions. Although it is difficult to say why the dropout rate was low, the environment may have influenced the active participation and continuity of family caregivers with dementia. Continuous

learning of mindfulness is important, and if they felt the benefits of the program, the participants may have felt motivated to continue.

However, because these reasons may be fragmentary, it is necessary to verify the low dropout rate of the programs used in the studies examined in this review by accumulating randomized controlled trials.

4.1.2 Effectiveness of the Program in Improving Self-Compassion of Family Caregivers with Dementia

The results of the included studies indicated that the mindfulness-centered intervention program was effective in improving self-compassion among family caregivers with dementia, although there were differences in the number of interventions, intervention time, and types of meditation among the studies.

There are several reasons that the mindfulness-centered program is useful, including “kindness toward oneself,” which consists of self-compassion; “common humanity,” which is not something that is experienced in isolation but is considered to occur in relationships with others; and “mindfulness,” which is the ability to accept events that occur as they are. Mindfulness is the first step in improving self-compassion,¹¹⁻¹² and it is said to have a positive impact.³⁰⁻³³

Mindfulness is defined as “deliberately focusing on the experience of the present moment, without evaluation, without preoccupation, and simply watching”³⁴, and family caregivers of those with dementia may have objectified their own feelings and cognitions arising from daily care and caregiving through the mindfulness program. Although it may be a positive for family caregivers of those with dementia to objectify their own situation through the program, previous studies have shown that, by objectifying their own care, family caregivers may concern that their own care is inadequate, and their sense of competence may decrease.³ These individuals may report that introspection seems to generate negative thoughts about the caregiver’s situation and the person with dementia, leading to feelings of guilt and shame.³⁴ Furthermore, family caregivers of those with dementia may perceive self-compassion as selfish and self-obsessive and describe the possibility of resisting self-compassion.³⁵ Although self-compassion is considered by many to be an innate right,¹¹⁻¹² these perceptions of family caregivers may have a greater inhibitory effect on improving self-compassion than those who provide care to people without dementia.

We did not find any previous studies that had the goal of verifying the effectiveness of a mindfulness-centered program and compared caregivers who were providing care to someone with dementia to those who were providing care to someone who did not have dementia. However, it is possible that family caregivers of those with dementia may experience a decreased sense of competence and a greater sense of guilt and shame than other caregivers if they objectify their care and other aspects of their lives,³⁶⁻³⁷ which may cause these caregivers to experience greater psychological distress than other caregivers, increasing the feelings of guilt and shame that may arise through caring for people with dementia and are associated with the onset of depressive symptoms.³⁸⁻³⁹ To improve self-compassion of family caregivers of those with dementia, mindfulness practices that are specialized for family caregivers with dementia are necessary. These programs should incorporate sufficient content for learning “self-kindness” and “a sense of common humanity,” which are other components of self-compassion, so that the participants can fully experience compassion toward themselves. Furthermore, some studies have suggested that feelings of guilt on the part of family caregivers of individuals with dementia are influenced by cultural beliefs and gender,⁴⁰ in addition to the caregivers’ sense of moral responsibility for caring for patients with dementia. Therefore, it is necessary to construct a program that takes into account social and cultural background of Japan.

Of the studies examined in this review, only study 2 was an intervention study that used an online system (Zoom). In both studies 2 and 3, caregivers who dropped out of the programs cited difficulties in attending due to their responsibilities as caregivers and related time constraints. This difficulty was also reported in a study examining Japanese family caregivers of those with dementia,³ and the results showed that Japanese family caregivers were unable to confide in others about their current situations⁴¹ and did not actively receive support.⁴² Considering the time constraints of caregiving and the daily life of those who provide care for people with dementia, as well as the expansion of support to the community, it is necessary to create support opportunities both in-person and online.

4.2 Possibility of Bias in the Review Process

The Cochrane Handbook²³ recommends that a review be conducted by two or more independent researchers. In this study, two researchers conducted the review,

followed by discussions among three researchers, including two other researchers, until a consensus was reached. This is considered to have increased the reliability of the results. The RoB 2 automatically evaluates the risk of bias, including the overall evaluation, after examining the signaling questions in the five evaluation domains; it is considered a suitable tool for objective evaluation.

5. Limitations of the Study and Future Prospects

Although only randomized controlled trials were included in this study, there were differences in eligibility and exclusion criteria for the participants, and the intervention methods used also differed. In addition, although each program led to improved self-compatibility, many of the programs did not identify the therapists, and it is unclear whether the effectiveness of the programs implemented in the studies examined in this review was maximized for family caregivers of those with dementia. Further randomized controlled trials are needed to establish a methodology to improve self-compassion among family caregivers of patients with dementia while ensuring the quality of the intervention skills of therapists.

6. Conclusion

This review examined randomized controlled trials to uncover a methodology that could improve self-compassion among family caregivers of patients with dementia and suggested the usefulness of a mindfulness-centered program. However, due to the paucity of previous studies, the effectiveness of such a program is not definitively established, and further randomized controlled trials should be conducted.

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