Review Article

Social Support on Family Caregivers of Alzheimer Patients: A Systematic Review

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ABSTRACT

Background and Purpose: Family caregivers of patients with Alzheimer face many challenges when caring for them. The patients need not only the care of health professionals but also social support. Therefore, this study aimed to summarize the existing studies on social support for family caregivers of Alzheimer patients in a systematic review.

Materials and Methods: In this review, the search was done in domestic (Magiran, SID) and foreign (Web of Science, Scopus, ProQuest, PubMed) databases as well as Google Scholar from 1990 to August 2021, according to the PRISMA (Preferred Reporting Items for Systematic Reviews) statement. The Cochrane and STROBE checklists were used to evaluate the quality of the articles.

Results: Out of 709 articles on social support in family caregivers of Alzheimer patients, 7 entered the final list. The number of family caregivers participating in these studies ranged from 81 to 648. The mean age of caregivers in all studies was over 50 years. The studies emphasized the importance of improving social support in family caregivers of Alzheimer patients. Most study studies were conducted in America, which included all the interventional studies in this systematic review. In most studies, social support's role in reducing family caregivers' problems and promoting their satisfaction was important.

Conclusion: Creating social networks and encouraging the use of these supports will be very helpful in reducing the problems of family caregivers of Alzheimer patients. More attention to health literacy is likely useful as a revelation of the need for social support in family caregivers of Alzheimer patients and the government.

Keywords: Social support, Social network, Family caregivers, Informal caregivers, Alzheimer disease, Systematic review

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1. Introduction

Alzheimer disease is a chronic, progressive, and neurodegenerative disease characterized by symptoms of loss of cognitive abilities and the development of behavioral disorders [1]. Diagnosis of Alzheimer disease causes great fear and panic in the patient, relatives, and caregivers of the infected person [2]. Most Alzheimer patients are looked after at home by family members, and these caregivers are under pressure because of their increasing needs [3].

Alzheimer caregivers include formal and informal caregivers. Formal caregivers are trained individuals who generally care for an Alzheimer person at a care center [4]. On the other hand, informal caregivers are non-professionals who care at home [5]. Family members are the main group of non-professional caregivers, as 80% of Alzheimer patients are responsible for their care [6]. The burden on family caregivers includes physical and psychiatric symptoms, particularly depression—commonly found in family caregivers with rates of up to 70% described [7]. However, caring for patients at home creates different physical, psychological, and social conditions for caregivers. One of the most affected aspects is individuals' social support and social networking, which are seen as a lack of opportunity for leisure activities, the inability to go out or work, and changes in daily family life [6].

Social support is a complex concept that has several definitions [6]. According to Cohen's definition in 2004, social support is a social network that provides people with psychological and tangible resources to cope with stressful living conditions and daily problems. Social support is divided into 3 types: instrumental, informational, and emotional. Instrumental support is essentially the same as material resources such as food and money. Informational support includes providing information or suggestions that enable a person to cope with problems and difficulties, and emotional support includes loving, caring, and understanding the other person [7]. Social network, social support, and social relations terms are often used as synonyms. Social network, however, refers to the group of people with whom the individual keeps contact or some social bond and mainly involves quantitative aspects of social contacts [7].

Although caring for Alzheimer patients can have positive aspects for caregivers, the importance of negative aspects cannot be overlooked due to the increasing burden of care that can be very challenging for them [8-11]. The burden on family caregivers includes physical and psychiatric symptoms, particularly depression, commonly found in family caregivers with rates of up to 70% described [7]. In most cases, family caregivers are not prepared to provide care. On the other hand, insufficient knowledge in the care of Alzheimer patients may lead to poor care. Caregivers with inadequate health literacy are among these people. Health literacy uncovers the needs of caregivers and encourages them to participate in support groups and use social support [8].

Family caregivers are the most important source of care for patients and the health care system. Therefore, the issues of caring for older adults with Alzheimer and the economic, care, health, and family burden are considered by the health systems of countries. Therefore, paying attention to the concept of social support and increasing awareness in studies can play a significant role in solving the problems facing family caregivers of people with Alzheimer disease [9]. Therefore, this study aimed to evaluate social support studies in family caregivers of Alzheimer patients in a systematic review.

2. Materials and Methods

The present study was a systematic review with the research question, "What is the status of social support in Alzheimer family caregivers?" The study was based on the PRISMA (Preferred Reporting Items for Systematic Reviews) statement [10].

Data collection

A comprehensive electronic search of Iranian study in Persian (Scientific Information Database (SID), Magiran), in English (Web of Science (WoS), Scopus, ProQuest, and PubMed), and in Google Scholar search engine were performed with keywords of social support [MeSH], social networking [MeSH], family caregiver [Non-MeSH], informal caregiver [Non-MeSH, MeSH], Alzheimer disease [MeSH] with AND and OR functions which were published abroad from 1990 until August 2021. The language of the articles was either Persian or English. Articles were selected based on the PRISMA2020 checklist [11]. The search strategy in the PubMed database has been as follows:

("Social support"[All Fields] OR "social network"[All Fields]) AND "family caregivers"[All Fields]) OR ("Informal caregiver"[All Fields]) AND ("alzheimer s"[All Fields] OR "alzheimer disease"[MeSH Terms]) OR ("alzheimer"[All Fields] AND "disease"[All Fields]) OR ("alzheimer disease"[All Fields] OR "alzheimer"[All Fields] OR "alzheimers"[All Fields] OR "alzheimer s"[All Fields] OR "alzheimers s"[All Fields]) AND (1990:2021[pdat]).

This study included clinical trials, experimental, quasi-experimental, and all interventional trials, and cross-sectional articles regarding social support for family caregivers of Alzheimer patients. The target group of the included studies was family caregivers of Alzheimer patients who were taking care of the patient at home in line with the purpose of the study.

Data selection

All the studies considered for the systematic review met the following inclusion criteria. The analysis should be quantitative and original, the studies must be about social support, the study must be about family caregivers, and the main disease must be Alzheimer. However, studies failed to meet these criteria, and those whose abstracts were without full text or included formal caregivers were excluded.

Data extraction

After recruiting all relevant studies through systematic search, duplicated articles were excluded. Irrelevant articles, which were identified by titles, abstracts, or full texts, were also excluded. To review the articles, the titles, abstracts, and, finally, the whole text of the article were studied. The search process, selection of articles, qualitative evaluation of articles, and data extraction were performed by two researchers independently. A third party re-examined any disagreement between the researchers. The required data were extracted after reading the abstract and full text of the eligible articles. The researchers used the PRISMA checklist for reporting systematic reviews. The required data were extracted from the articles using a checklist that included the first author's name, year of publication, title, type of study, country, measurement tool, and results.

Quality appraisal

The Cochrane and STROBE checklists were used to evaluate the quality of the articles. Cochrane checklist was used to examine biases in selection, performance, diagnosis, data collection and reporting, and other biases in interventional studies [12, 13] (Table 1). The other studies (descriptive cross-sectional) were assessed with STROBE checklists (Table 2).

3. Results

Study selection

In the first step, 709 articles related to the study of social support in family caregivers were found. Of these, 205 studies were excluded due to duplication. Of the remaining 504 articles, abstracts of all studies were reviewed, and 387 articles were deleted due to irrelevance. In the second step, the full text of the remaining 117 articles was reviewed, of which 89 articles were removed from the study process due to a lack of inclusion criteria. Also, the full text of 9 articles was not available. Then 19 studies entered the qualitative evaluation stage, and finally, 7 articles were used (Figure 1).

Study characteristics

The studies were descriptive cross-sectional and performed before and after educational interventions on family caregivers of Alzheimer patients in other countries. Thus, 5 studies were descriptive-cross-sectional [3, 14-17], and 2 were interventional studies [18, 19]. Four studies were conducted in the United States [15, 17-19] and 3 others in China [16], Turkey [3], and Spain [14]. Different tools have been reported in these studies. The most well-known tools are MSPSS (Multidimensional Scale of Perceived Social Support) [3] and Duke-UNC-11 [14]. The number of home caregivers ranged from 81 to 648 in various studies. The mean age of caregivers in all studies was over 50 years.

Results of syntheses

All studies discussed the prominent role of society and social support networks. Also, in interventional studies [18, 19], the positive effect of interventions in social support was seen. Thus, in the intervention in the United States, the study focused on improving communication between family members so that individuals were encouraged to attend support groups every week. Methods such as face-to-face and telephone counseling were used to achieve this goal. The intervention was performed over 5 years. Thus, follow-ups were performed at the beginning of the first year (beginning of the study), 4 months, 8 months, and 12 months later. They are colorful and have good social support [18]. In another intervention in the same country in New York City, before the intervention, both intervention (22.7%) and control (25.1%) groups did not differ significantly in terms of the amount of support groups. However, after receiving the intervention, this amount in the experimental group reached 58.9% and in the control group 42.3%. All caregivers were satisfied with the social services provided and regularly attended support group meetings, although they also used telephone counseling facilities [19].

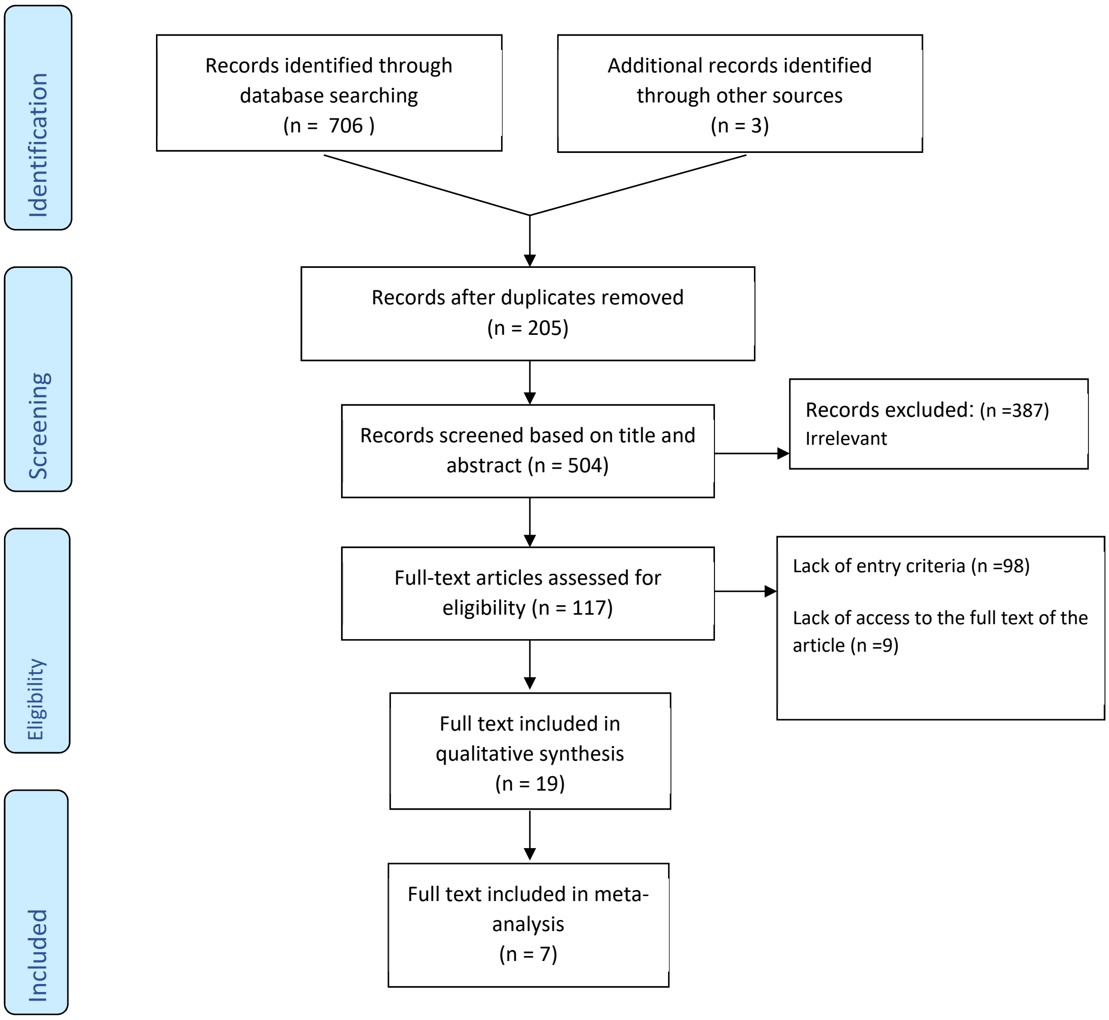

Figure 1. Systematic entry chart

Gibson et al. called for caregivers to comment on whether service providers or the general public properly understood their needs. Almost half (45.7%) acknowledged that service providers perform poorly in their area. The vast majority (84%) felt that the general public did not understand them properly. Despite this, 86.3% of caregivers felt they were coping and adapting to their situation [15].

4. Discussion

In this review, studies based on social support in family caregivers of Alzheimer patients were systematically reviewed, and finally, 7 articles were analyzed. This paper aims to summarize the existing studies on the social support of family caregivers of Alzheimer patients.

Table 1. Review of the intervention articles based on Cochrane evaluation checklist

% of Yes Answers	Free of Other Bias	Free of Selective Reporting	Incomplete Data Addressed	Blinding	Allocation Concealment	Adequate Sequence Generation	Author
50%	Y	?	Y	?	Y	?	David L. Roth [19]
83%	Y	Y	N	Y	Y	Y	Patricia Drentea [18]

Y: Yes; N: No; ?:Ambiguous

Table 2. Details of social support studies in family caregivers of Alzheimer patients

First Author	Year	Title	Social Support Measurement Tool	Country	Type of Study	Result	Qualitative Assessment
David L. Roth [19]	2005	Changes in social support as mediators of the impact of a psychosocial intervention for spouse caregivers of persons with Alzheimer disease	Stokes Social Network List	USA	Interventional	Increasing the number of supportive people, satisfaction with support and assistance to family caregivers increased significantly. The intervention showed increased satisfaction with the social support network, significantly reducing caregivers' depression.	-
Patricia Drentea [18]	2006	Predictors of improvement in social support: Five-year effects of a structured intervention for caregivers of spouses with Alzheimer disease	Stokes Social Network List	USA	Interventional	There was an increase in satisfaction. Higher spouse caregivers had higher levels of emotional support, more contact with loved ones, and more social networks with loved ones.	-
Sabire Yurtsever [3]	2013	The relationship between care burden and social support in Turkish Alzheimer patients family caregivers: Cross-sectional study	Multidimensional Scale of Perceived Social Support (MSPSS)	Turkey	Cross-sectional	Motivate social support networks and encourage caregivers to use this support and cope with the problems facing family caregivers of Alzheimer's patients	11
Sheung-Tak Cheng [16]	2013	The social networks of Hong Kong Chinese family caregivers of Alzheimer disease: Correlates with positive gains and burden	Social Convoy Questionnaire	China	Cross-sectional	Caregivers take on responsibilities for the family's collective wellbeing, especially when they are often isolated and frustrated, and when they do not have adequate social support and family support, they may even lose contact with their loved ones.	16
Grace Jeongim Heo [17]	2014	Religious coping, positive aspects of caregiving, and social support among Alzheimer disease caregivers. Clinical Gerontologist	15-item measurement of social support	USA	Cross-sectional	Religious adjustment was positively correlated with social care and support, while low religious adjustment was associated with depression.	13
Allison K. Gibson [15]	2014	Exploring the service and support needs of families with early-onset Alzheimer disease	-	USA	Cross-sectional	Caregivers need a range of formal services and informal support from family and friends. Caregivers also stated that the public service providers did not well understand their needs	13
José Manuel Hernández-Padilla [14]	2021	Perceived health, caregiver overload and perceived social support in family caregivers of patients with Alzheimer: Gender differences	Goldberg's General Health Questionnaire (GHQ-28)	Spain	Cross-sectional	Poor perceived health, high care burden, and perceived social support were higher in women than men. Perceived social support affected the emotional health of family caregivers of Alzheimer patients. Its effect was different according to gender and was higher in women	14

Female caregivers are usually in a worse situation than male caregivers, with a significantly higher burden of care. On the other hand, social support is a moderating factor in reducing the burden of care. In women, perceived social support is a mediating variable between perceived social support and the burden of care. However, men respond differently to the responsibilities they are given. Therefore, gender differences in the care of Alzheimer family patients cannot be ignored [14].

Another study concluded that younger caregivers usually communicate better and more effectively with social networks and can adapt to problems [3]. Perhaps the higher level of education and health literacy of younger caregivers can be attributed to this. In other words, family caregivers can use health literacy to prepare for care [8, 20]. Caregivers of Alzheimer patients usually have less social support because they typically care for the patient alone [3, 14]. As a result, they bear a high burden of care and suffer more health problems than other caregivers [21].

Results of two other studies concluded that the support of the medical staff is very important for family caregivers, especially if the caregiver is over 50 years old, a woman, married, has a low level of education, a sick spouse, and a long period of care [3, 14]. It is necessary to know the needs of family caregivers and their health status and to design programs to reduce the burden of their care. What is certain is that these programs should be monitored regularly [3].

The results of an intervention in the USA indicated that emotional support is one of the dimensions of social support that has the greatest impact on maintaining a social network. One reason for satisfaction is emotional support to help cope with changes in family caregivers' lives [18]. In social support, satisfaction with emotional support is sometimes seen more than instrumental support. Probably caregivers believe that finding someone to listen to their concerns is not easy, so they feel very satisfied when they receive emotional support [13, 20-22]. On the other hand, living with Alzheimer patients leads to loneliness, so it is possible that emotional support programs and meeting other people can also lead to satisfaction.

The finding of another study showed that increasing satisfaction significantly reduced depression in family caregivers of Alzheimer patients [19]. Also, in a study conducted in Spain, those with less religious compatibility were more likely to be depressed, and positive religious adjustment positively and directly affects social support. People with stronger religious beliefs also have higher social support [17]. Therefore, interventions should pay attention to individuals' religious and cultural beliefs.

Training programs have had a positive effect on increasing the social support of caregivers. Despite improvements in various dimensions of social support, improvements in satisfaction are often seen as a reduction in stress and depression assessments. On the other hand, the satisfaction created is independent of the amount of aid received or the size of the social network [16].

Results of one study concluded that social support affects the burden of care and the rate of depression. Thus, the higher the social support for caregivers, the lower the burden of care, and the lower the burden of care, the higher the social support, and the lower the depression [17]. However, the results provided enough evidence to suggest a significant correlation between social support and satisfaction, depression, burden of care, and religion that should be investigated further.

In the present study, the number of social support studies in Asia [3, 16] and Europe [14] was less than in the United States [15, 17-19]. Also, all interventional studies were related to the United States [18, 19]. Due to the high number of Alzheimer patients and the number will increase, all communities should have a wide view of social support.

Sometimes the services provided do not meet the needs of family caregivers. On the other hand, social support programs are not always implemented properly [15]. For example, the COVID-19 pandemic is a challenge for improving health during lockdown. Unfortunately, the concern expressed for the welfare and the health of the Elderly contradicts the actions undertaken for their health and welfare [22]. Therefore, recognizing the needs of this target group is essential, which can be achieved by conducting qualitative studies.

Despite the studies conducted in this systematic review, limited access to some databases and lack of access to the full text of some articles can be considered limitations of this study, which have been effective in selected articles.

5. Conclusion

Because family caregivers of Alzheimer patients usually carry a large burden of care due to a lack of social and family support, the high care load on caregivers will greatly impact their social and family life. Creating support networks and encouraging the use of these supports and the positive interaction of other family members, as well as improving the performance of current social networks, can reduce the problems caused by care. Also, considering the important role of interventions and the lack of interventional studies in this field, it is suggested to design appropriate programs to promote informal caregivers' health literacy and introduce and provide social support.

Ethical Considerations

Compliance with ethical guidelines

This review study was done based on standard ethical issues. Department of Health Education and Health Promotion of Mashhad University of Medical Sciences approved this research.

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Authors contributions

Both authors equally contributed to preparing this article.

Conflict of interest

The authors declared no conflict of interest.

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