Review Article

Informal Caregivers and Care Burden in Iran: Systematic Review and Meta-Analysis

Abstract

Background: The increase in the average age of the population, the decrease in the size of the household and rising in the number of working women impose an increasing burden on home caregivers in Iran. The aim of this study was to measure care burden of informal caregivers in Iran through systematic review and meta-analysis of existing literature. **Materials and Methods:** A systematic review was conducted by using national and international databases of Scopus, PubMed, Embase, Web of Science, SID, Magiran, and IranDoc papers in English and Persian language up to the first half of 2020. In this meta-analysis, we calculated the pooled care burden and 95% confidence intervals in Statistical Software For Data Science (STATA) V.15. **Results:** Forty-four papers were included in the current study based on inclusion and exclusion criteria comprising of 8626 samples. Pooled mean of Burden of Care was 52.01 (95% CI: 48.21-55.82). Highest pooled mean(SD) of care burden (64.37) was related to caregivers of schizophrenia patients (95% CI: 56.09–72.64). Highest care burden (53.45) was observed in most deprived areas (95%CI = 47.05–59.86). A statistically significant relationship was observed between caregivers gender and care burden ($p < 0.05$). **Conclusions:** The reported care burden of informal caregivers requires the establishment of a support system to control mental and physical stress. Due to the dispersion and cultural diversity in Iran, more studies are needed to obtain more accurate data.

Keywords: *Caregiver burden, Iran, meta-analysis, schizophrenia, systematic review*

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Introduction

Sickness is an inseparable part of human life, and every person becomes sick many times during his/her life. Depending on disease severity, one has to receive different kind of care in different setting including medical centres, nursing homes, or their own place of living homes. Modern medicine puts more emphasis on shorter hospital stays with improved follow-ups in home-care setting, which is an affordable alternative for both patient and the hospital. Based on this strategy, the role of family members who are called informal caregivers is brilliant in providing care.[1] They provide a variety of daily, typically unpaid assistance, such as health care, nutrition, bathing, and financial management, to chronically or incapacitated patients.[2]

In European countries, 80% of care is provided by informal caregivers[3] 5.7 million informal caregivers are providing services in the United Kingdom (UK), that is, one out of every six households is involved in providing care. Free services usually provided by family, friends, or volunteer groups to people with chronic diseases and mental/physical disabilities begins with the onset of hospitalization and usually continues until recovery or death.[4]

Long-term living of caregivers with the patient may lead to negative consequences which are called as caring burden. Care burden is a multidimensional, phenomenon having physical, psychological, social, and financial dimension which affects those who care for the patient.[5] These consequences are mainly due to changes in individual lifestyle and affect general health, performance, socioeconomic, and psychological status as well as the familial relationship.[6]

It is estimated that elderlies would constitute 21.7% of Iran's population until 2050 which in turn will have adverse economic, health, and social welfare effects.[7] Additionally, the absence of evidence-based approach to decision-making for addressing issues of

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informal care givers might threaten their health which in turn will impose further burden to health system.[8]

Even with no new probable epidemics in Iran, the health system will be forced to provide extra care for the increasing elderly population who suffer from various chronic diseases and have to rely on informal caregivers[9] to respond to problems caused by changing population structure in Iran and facing nurses' burnout.[8] Caregivers' burden of care and vulnerability to care problems will increase as their caring role is increased, which can be avoided by early diagnosis and development of proper interventions.[10]

Various tools have been used to measure caregivers' burden of care in different diseases in the world[11] and different levels of caregiving burden have been reported.[12] In a systematic review conducted by Chioa *et al*.,[13] behavioral and mood problems have been identified as major care burden among caregivers. The results showed that this rate has been reported differently in different studies according to the gender and age of the caregiver. Therefore, identifying care burden and the variables affecting it can lead to predicting early interventions, so that caregiving burden can be reduced or its effects delayed.[13]

Various studies have measured the burden of care in various diseases in Iran and reporting different values for burden of care.[14,15] These are not comprehensive and are not suitable for policy making and providing accurate advices. Therefore, the question raised in this study is the present study, which is part of a doctoral dissertation, aimed to evaluate and compare the care burden of informal caregivers in Iran.

Materials and Methods

The present study reports a systematic review of the care burden of informal caregivers in Iran. Domestic and international databases including SID, Magiran, IranDoc, Scopus, PubMed, and Embase were systematically searched in May 2019. "AND" and "OR" operators were used to search English databases for Key words and Mesh terms such as informal caregiver, care burden and Iran [Table 1]. Persian words equivalent to these English terms were used in national electronic databases without considering the time limit [Table 2]. We also searched Google Scholar using Persian and English search terms to make sure no relevant papers were left out.

Table 1: Key components in search databases with synonyms

Components	Keywords	synonyms
Population	Informal Caregiver	Hidden patient, Caregivers, Family caregivers, Family care, Major caregiver
Issue	Care burden	Caregiving strain, Burnout
Area	Iran	-

Eligibility criteria were as follows: 1) English and Persian cross-sectional studies that reported mean and standard deviation for burden of informal caregiving in Iran. Written in English or Persian and papers were excluded if 1) they were interventional, case-control, cohort and systematic review studies; 2) they measured caregiver depression, depressive symptoms caregiver burden; 3) Dissertations or abstracts of studies s whose full texts were not accessible. Cross-sectional studies that did not report the mean burden of care and we could not retrieve it by correspondence with author(s).

In the first phase, titles and abstracts of 373 retrieved papers were studied. In the next phase, full texts of 141 remaining were studied, which led to 47 studies entering qualitative evaluation phase [Details are presented in Figure 1]. The methodological quality of the studies was assessed using Joanna Briggs Institute (JBI) Checklist.[16] It is an 8-item instrument designed for quality evaluation of cross-sectional studies. Each item is scored between 0 and 1. Score 1 is given to the study that meets the criteria and if the study is not sufficient or no explanation of the criterion is available zero score is given. It should be noted that in this check-list item 6 "refers to Confounding factors" which was not carried out in any of the studies, so the score for all studies was calculated as the same. So total score range is between 0 and 7 points. After analysing and determining the cut-off point by "visual binning" in Statistical package for the social sciences (SPSS) ver. 22.0 (Armonk, NY: IBM Corp), score of less than 3 was defined as low quality, 4 to 5 as average quality, and 6 to 7 as high quality. In this study, studies with average and high quality were accepted.[14,17-56] In order to minimize errors in data extraction, all data were extracted in a date extraction form by two researchers (Reza Goudarzi, Leila Agoush) separately [Table 3]. In cases of disagreement, consensus was reached through a senior investigator.

After consensus, 3 articles were excluded because of low quality scores and 44 articles were included. We selected burden of care as the outcome measure which has been measure with different questioners in retrieved studies, in order to ensure homogeneity of the results, we rescaled the results of the outputs in the range of zero to one hundred. Then, we calculated standard deviation based on mean.

We performed meta-analysis using meta command in Stata 15, Forrest plot diagrams were drawn in which the size of each square indicates the sample size and the lines indicate the confidence interval of approximately for each study. In this study, I^2 and Q index were determined as the percentage of heterogeneous criteria of articles. The I^2 values lie between 0% and 100% where 0% indicates no observed heterogeneity, and larger values show increasing

Table 2: Retrieved articles in searching selected databases in the first iteration

Database name	Keywords	Founded articles	Date of search	Deleted articles	Final selected articles
Noormags	Informal caregiver-Family caregiver-burnout-care burden	38	No time restriction	16	2
SID	Informal caregiver-Family caregiver- burnout-care burden	56	No time restriction	16	11
Magiran	Informal caregiver-Family caregiver-burnout-care burden	32	No time restriction	11	3
Civilica	Informal caregiver-Family caregiver-burnout-care burden	12	No time restriction	9	0
Irandoc	Informal caregiver-Family caregiver-burnout-care burden	18	No time restriction	8	1
Medical Journals Database	Informal caregiver-Family caregiver-burnout-care burden	25	No time restriction	18	1
Google scholar	Family caregiver and care burden and Iran	24	No time restriction	11	3
PubMed	((((((((“informal caregiver”[Title/Abstract]) OR (“hidden patient”[Title/Abstract])) OR (“caregivers”[Title/Abstract])) OR (“family caregiving”[Title/Abstract])) OR (“family care”[Title/Abstract])) OR (“major caregivers”[Title/Abstract])) AND((“care burden”[Title/Abstract])) OR (“caregiving strain”[Title/Abstract])) AND((Iran[Title/Abstract])))))))))	11	No time restriction	10	9
Web of Science	TS = (“informal caregiver” OR “ Hidden patient ” OR “ caregivers ” OR” Family caregivers ” OR “ major caregiver ”) ANDTS = (“Care burden ” OR “ caregiving strain ”) AND ADDRESS (Iran)	127	No time restriction	77	14
Scopus	((TITLE-ABS-KEY (“informal caregiver”) OR TITLE-ABS-KEY (“Hidden patient”) OR TITLE-ABS-KEY (“caregivers”) OR TITLE-ABS-KEY (“Family caregivers”) OR TITLE-ABS-KEY (“family care”) OR TITLE-ABS-KEY (“major caregiver”))) AND ((TITLE-ABS-KEY (“Care burden”) OR TITLE-ABS-KEY (“caregiving strain”))) AND (TITLE-ABS-KEY (iran))	16	No time restriction	10	2
Embase	‘informal caregiver’:ti, ab, kw OR ‘hidden patient’:ti, ab, kw OR ‘caregiver’:ti, ab, kw OR ‘family caregivers’:ti, ab, kw OR ‘family care’:ti, ab, kw OR ‘major caregiver’:ti, ab, kw AND ‘care burden’:ti, ab, kw OR ‘caregiving strain’:ti, ab, kw AND iran: ti, ab, kw	5	No time restriction	2	0
Cochrane	(“informal caregiver”):ti, ab, kw OR (“Hidden patient”):ti, ab, kw OR (“caregivers”):ti, ab, kw OR (“Family caregivers”):ti, ab, kw OR (“family care”):ti, ab, kw (Word variations have been searched) OR (“family care “):ti, ab, kw OR (“major caregiver “):ti, ab, kw OR (“family care”):ti, ab, kw AND (“Care burden”):ti, ab, kw OR (“caregiving strain “):ti, ab, kw AND (“Iran”):ti, ab, kw	7	No time restriction	0	0
		371		188	46

heterogeneity.[57] Since there was heterogeneity among studies, random effects method[58] and subgroup analysis according to type of disease was used to estimate care burden of informal caregivers in Iran. The sensitivity analysis was performed to evaluate the effect of each study on the inclusive result which did not show statistically significant changes in the overall mean. Finally, regression was evaluated to identify the interaction effect of demographic characteristics on the mean of care burden.

Ethical considerations

Researchers tried to act in an unbiased way to analyze the retrieved data of articles. ethics committee of Kerman University of Medical Sciences, Iran approved this study (IR.KMU.REC.1400.549).

Results

Characteristics of the included studies

Totally, 373 articles were identified. After checking the inclusion, exclusion criteria and quality appraisal, 44 articles were included in this meta-analysis [Figure 1]. The study by Noori Khajavi[43] is brought twice since it has reported two separate group of patients (Schizophrenia and psychological patients). All studies were published between 2001 and 2020 in different cities of Iran. Up to the year 2000, there was no report of care giver burden in Iran [Table 3]. Majority of studies (n = 15 studies) were conducted in capital of Iran (Tehran).

The most and least care burden (53.45; 95%CI = 47.05–59.80) and 50.90 (95%CI = 46.44–55.36) was reported in areas which belong to the lowest and highest Degree of

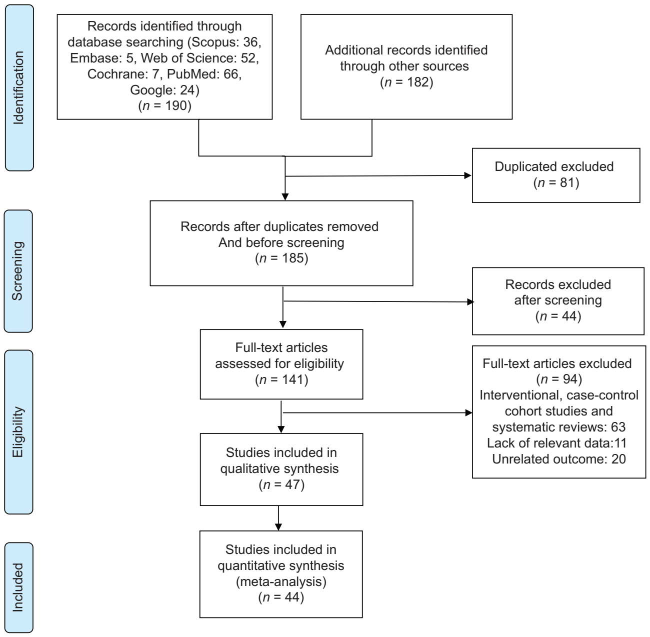

Figure 1: Flow chart of detailed procedure of literature search and study selection

Development according to a classification by Nazmfar *et al*.[59] based on cultural, social, economic, educational, physical, health, and infrastructure indicators, respectively. Ten different instruments were used to measure caregiver burden in the 44 studies. Most of studies used (Zarit Burden Interview) (16 studies). Most studies (n = 44 studies) reported mean of care burden with standard deviation and 3 studies reported just mean. The majority of studies were done in both genders while 5% of studies were conducted only among women (2 studies). The biggest and smallest sample size related to Malakuti *et al*.[55] (N = 1200) and Noori Khajavi *et al*.[54] (N = 50) study respectively. The mean (SD) age of the caregivers was 42.60 (5.80) years which ranged from 34 to 57 years who cared patients whose average age was 39.45 (24.3) years. Most of caregivers were female (62%), housekeepers (46.20%), parents (40.60%), married (76.40%), and had under-diploma education (61. 40%).

Pooled prevalence

Pooled effect of burden of care was 52.01 (95% CI: 48.209–55.820). Most of pooled mean of care burden was related to caring of schizophrenia patients 64.37 (95% CI: 56.09–72.64) and the lowest was related to caring of the elderly 30.0 (95% CI: 23.55–36.45) [Figure 2]. Regression analysis showed a direct relationship between caring burden and being a woman ($p = 0.05$) and inversely correlated with illiteracy ($p = 0.041$). No significant correlation could be established between any of patient age, caregiver's degree of relationship to the patient, job, and care burden [Table 4].

Analysis of heterogeneity and publication bias

In all analyzes including total and subgroups, we found evidence of heterogeneity among studies while I^2 ranged from 60.5% to 92%. Since 44 articles were included in our meta-analysis, publication bias was assessed using funnel plot.[60] There is no evidence of publication bias was found in the studies [Figure 3].

Discussion

Iranian caregivers suffer more than 50% from care burden. These caregivers are mostly female, parents, work as housewives similar to previous studies which showed three out of five caregivers were women (61%) and parent constituted the majority of caregivers.[61,62] However, in a Japanese study, spouses (55.9%) were the most who provided informal care.[62] Given that being female, increases caregiving burden by 0.41 times [Table 4] and the fact that most caregivers are women,[62-64] paying attention to the needs of female caregivers is importance in establishing supportive systems. While the highest proportion of caregivers in Iran and the United States are parents, the situation is different when it comes to the second most important group of informal caregivers. In the USA, children are the least important group (6%) but they are the second caregivers group in Iran, a situation similar to what has been reported in two Japanese's studies.[61,62]

The clear dissimilarity which exists between cultures and the role of children in the family can be considered as a motive for this matter.

On the other hand, the high life expectancy in Japan has led spouses to be able to look after each other. Although providing

Table 3: Summary of studies examining caregiver burden

Author	Year	Mean	Sample	Type of disease	Study location	Questionnaire	Quality score
Mollai *et al*.	2020	29	150	cancer	Tehran	ZBI*	6
Menati *et al*.	2020	60	130	dialyze	Tehran	Novak	7
Daystar *et al*.	2020	51	382	dialyze	Kerman	Novak	5
Hatefi *et al*.	2019	65	150	(SCi)**	Ilam	Novak	7
Shfiezadeh *et al*.	2019	32	315	Alzheimer ‘s	Tehran	Novak	6
Hajebi *et al*.	2019	56	172	schizophrenia	Tehran	ZBI	5
Rahmani *et al*.	2019	74	225	schizophrenia	Tabriz	ZBI	7
Asadi *et al*.	2019	45	152	psycho	Ahvaz	ZBI	7
Abbasi *et al*.	2019	46	154	cancer	Shahroud	Novak	7
Esmail motlagh *et al*.	2019	64	187	cancer	Kermanshah	Iranian Version of Caregiver Burden	4
Ahmadi *et al*.	2019	59	125	cancer	Tehran	Elmstahl	7
Masoudian *et al*.	2019	50	62	stroke	Semnan	Novak	4
Farzi *et al*.	2019	51	254	dialyze	Isfahan	ZBI	5
Rafati *et al*.	2019	51	382	dialyze	Kerman	Novak	6
Arab *et al*.	2019	56	117	child	Bam	Elmstahl	5
Ahmadi *et al*.	2018	59	85	leukemia	Tehran	Elmstahl	5
Rajabi *et al*.	2018	49	146	cancer	Tehran	Novak	5
Jafari *et al*.	2018	54	246	dialyze	Kermanshah	Novak	5
Ramezani *et al*.	2018	44	200	psycho	Sari	ZBI	4
Ghasemi *et al*.	2018	35.77	140	Heart (other)	Kerman	ZBI	5
Haghgoo *et al*.	2017	59	246	Psycho	Yasoj	Novak	7
Karimirad *et al*.	2017	50	220	Psycho	Tehran	Connor and Davidson resilience	4
Khazaeipour *et al*.	2017	44	163	(SCi)	Tehran	ZBI	7
Salmani *et al*.	2017	62	70	Cancer	Yazd	Elmstahl	5
Adib-hajbaghery *et al*.	2017	44	385	Child	Isfahan and Kashan	ZBI	7
Torabi chafjiri *et al*.	2017	23	407	Stroke	Guilan	Novak	6
Bamari *et al*.	2016	44	70	diabetes (other)	Zabol	ZBI	4
Vahidi *et al*.	2016	34	150	Cancer Brest (other)	Tabriz	ZBI	7
Nikmanesh *et al*.	2016	37	54	Dialyze	Zahedan	Novak	5
Shamsaei *et al*.	2015	58	225	schizophrenia	Hamadan	ZBI	5
Valizadeh *et al*.	2014	42	150	leukemia	Tabriz	Keegan-Wells	5
Bastani *et al*.	2014	71	150	Alzheimer	Tehran	Robinson	6
Mashayekhi *et al*.	2014	49	160	Thalassemia (other)	Jeroft	Elmstahl	5
Talebi *et al*.	2014	57	154	Dialyze	Rasht	ZBI	5
Salmanie *et al*.	2014	68	60	Cancer	Yazd	Novak	4
Abbasi *et al*.	2013	75	120	Dialyze	Gurgaon	Novak	6
Khatti dizabadi *et al*.	2013	30	194	Aging (other)	ghaem shahr	yang	5
Koohestani *et al*.	2012	65	140	Stroke	Arak	ZBI	6
Haresabadi *et al*.	2012	62	75	schizophrenia	Bojnord	ZBI	5
Abdollahpour *et al*.	2012	49	153	Alzheimer ‘s	Tehran	Iranian Version of Caregiver Burden	5
Noori khajavi *et al*.	2008	60	50	Psycho	Tehran	FBIS	4
Noori khajavi *et al*.	2008	73	50	Schizophrenia	Tehran	FBIS***	4
Mohammadi-shahboulaghi *et al*.	2006	60	81	Alzheimer ‘s	Tehran	Robinson	5
Malakuti *et al*.	2004	50	1200	Psycho	Tehran	FBIS	5
Navidian *et al*.	2001	47	125	Psycho	Zahedan	ZBI	6

* Zarit Burden Interview, **spinal cord injury, ***. Family Belief Inventory surveying

informal care is an inseparable part of Iranian culture which has been regarded as a value, we figured out the issue of caregiving in Iran is a relatively new research topic with first published study dating back to 2001 and most studies are conducted between 2018 and 2020. This might be explained by a variety of factors including aging population, Noncommunicable Diseases (NCDs) prevalence,[65] increased women employment, nursing burnout, smaller family size, and novel approaches

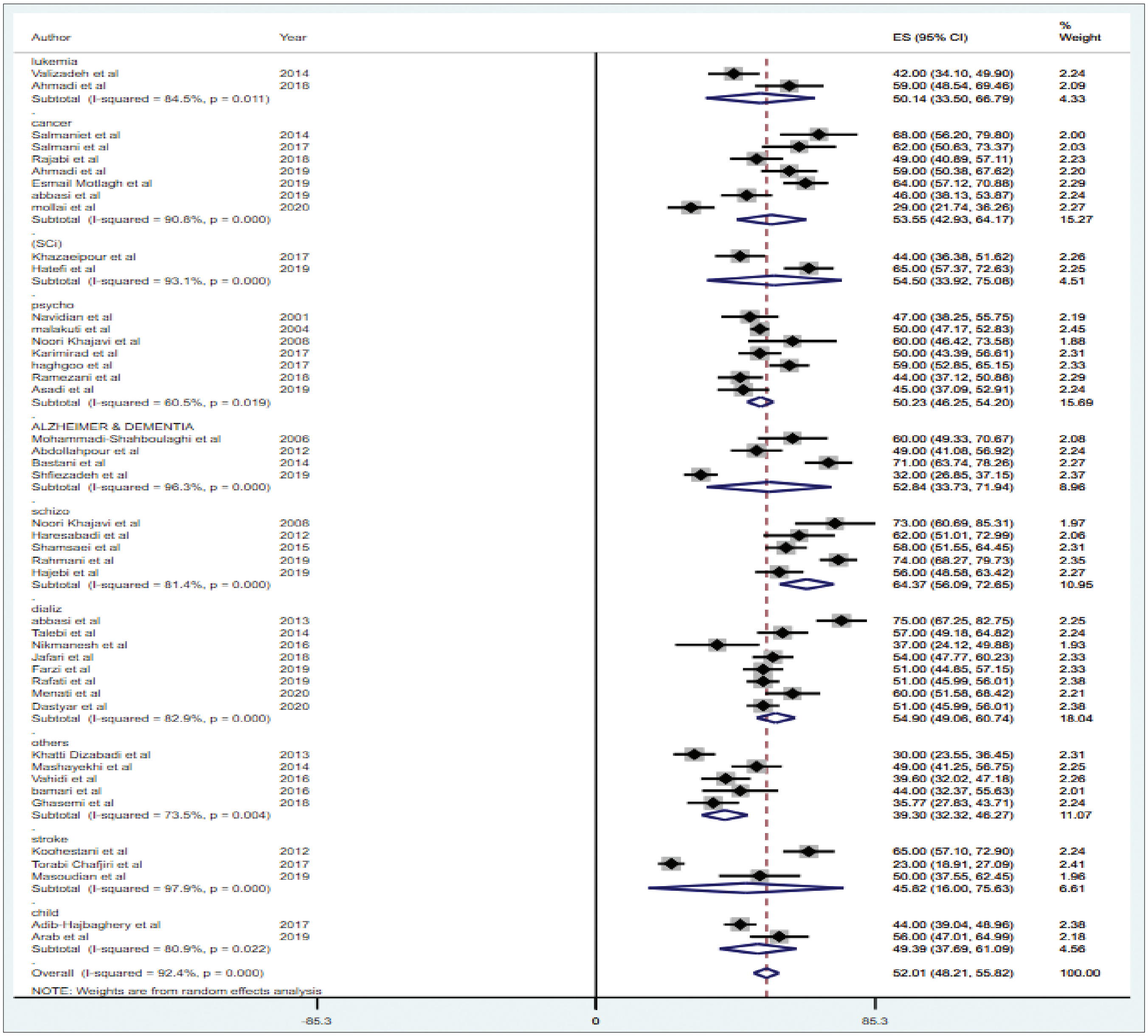

Figure 2: Forest plot of care burden of informal caregivers in Iran

to providing health services. This study indicated that lots of instruments have been used for measuring care burden with the Zarit Burden Interview as the most widely used questionnaire. This is similar to a study by Whalen *et al*.,[11] who pointed out the dominancy of this tool over other questionnaires for measuring the care burden. This might be explained by the relatively easier administration of the questionnaire and its better adoption with different cultures.

Although the average age of Iranian caregivers is less than Americans (49.4),[61] Europeans (64.7)[66] and Japanese (50.7),[62] but indicates a relatively high pressure over caregivers. Considering that most of the caregivers are themselves in their middle age, current informal care provision might bring in, many problems for caregivers in their subsequent years of life, which in turn adds extra burden to healthcare system which already suffers from shortage of human resources in many countries.

According to previous studies, low educated caregivers (illiterate or primary education) experience higher care burden than others.[67,68] Hence, providing training is expressed as one of the most important needs of caregivers to increase their capabilities to cope with the burden of care.[69] In contrast, our study, indicated that illiteracy has an inverse relationship with the caregiver burden. This can be explained by the fact that most studies have not reported illiteracy status and in two studies that have reported illiteracy rate, above 30% experienced low average burden of care. Our analysis indicated that caregivers in less developed regions of Iran experienced higher care burden, similarly existing

Table 4: Relationship between care burden and study variables

Parameter	Coefficient	Standard Error (SE)	*t*	*p*	Confidence interval[95%]	
Female	0.41	0.13	3.02	0.05	0.13	0.73
Male	0.18	0.13	1.33	0.192	-0.90	0.41
Parent	0.13	0.10	1.28	0.209	-0.81	0.32
Spouse	0.01	0.18	0.11	0.916	-0.32	0.31
Sibling	0.38	0.32	1.21	0.235	-0.21	1.04
Child	0.13	0.18	0.71	0.482	-0.20	0.52
Unemployed	0.22	0.20	1.07	0.295	-0.21	0.61
House caper	0.06	0.16	0.43	0.672	-0.20	0.30
Employ	-0.05	0.18	-0.30	0.769	-0.42	0.31
Illiterate	-0.66	0.31	-2.13	0.041	-1.21	-0.02
Sub diploma	-0.19	0.14	-1.36	0.184	-0.40	0.09
Educated	-0.10	0.18	-0.56	0.582	-0.40	0.20
Single	-0.14	0.26	-0.54	0.594	-0.63	0.30
Married	-0.07	0.10	-0.64	0.526	-0.21	0.10

Number of observations=45 f (14, 31)=5.66 *p*-value prob < 0.001 R-squared=0.71

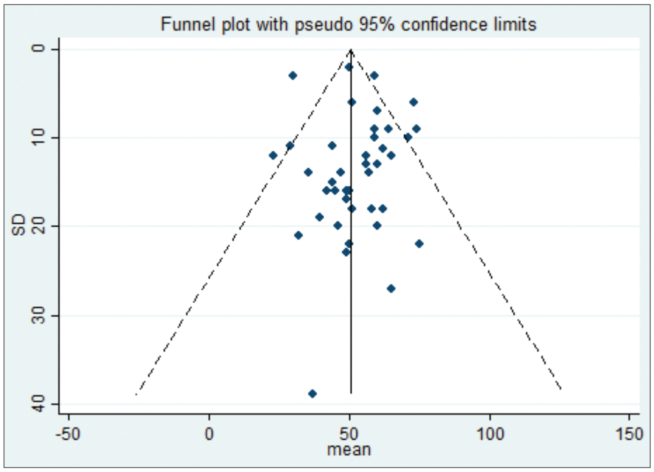

Figure 3: Annotated funnel plot of Standard Deviation (SD) by mean for the meta analysis of care burden of informal caregivers

literature shows a reverse relationship between care burden and urban development and access to financial and welfare facilities[70] rate of care burden is higher than mean value publicized by World Health Organization (WHO) for countries with similar average income Iran,[71] which increases attention to caregivers' needs to relieve the burden of care and prevent more severe injuries by using formal caregivers because family caregivers are part of the caregiver body.[12]

Our systematic review showed that mean of care burden varies in different diseases and ranging between 30% and 65%. Similarly, the latest report of caregivers published in the United States, mental illness is the most important problem for patients receiving care when the mean age is between 18 and 49.[61]

People who provided care for patients with schizophrenia reported high care burden similar to other studies who have reported high levels of care burden for this.[72,73] The severity of symptoms in patients with schizophrenia puts significant strain on families, it can begin with emotional reactions to illness and can continue with the stress of coping with disordered behavior, disruption of daily life, stigma, or limited involuntary hospital admissions.[74] Additionally, similar care burden is felt by Alzheimer's, dementia, and cancer caregivers which is confirmed by the study of Kim and Schulz on Comparative Analysis of Cancer Caregiving with Dementia, Diabetes, and Frail Elderly Caregiving. They also found that the burden of cancer care was higher than care burden of diabetes and elderly diseases, which was consistent with findings of this study.[75]

According to Systematic Review of Caregiver Burden following Stroke, the prevalence of caregiver burden was 25–54%[76] which matches our finding on care burden of stroke (45.82%). Shimoyama *et al*.[62] stated that the burden of peritoneal dialysis care in Japan is less than stroke, which is contrary to our findings for caregivers of dialysis patients, of course peritoneal dialysis at home can be an important cause for low care pressure of these caregivers because it does not interfere with the daily activities of the caregiver and the patient.

In Iran, like many Asian countries,[77] family care is considered as part of family duties, so it is important that policymakers have a specific plan for this large volume of voluntary assistance. Most of the included studies employed cross-sectional designs while we know that the care burden is not the same over time and most of the steps are not recognizable, so the use of longitudinal studies to periodically measure the burden of care is recommended. Studies used different scales to measure mean caregiver burden and this may have added to heterogeneity. One of the major concerns in systematic reviews of observational studies is controlling for the effect of confounders.[78] In the qualitative evaluation, no confounders factor was reported in studies. It is recommended to conduct review studies on family care support systems.

Conclusion

The average of care burden and a greater share of women indicate that the caregivers in Iran are facing relatively high burden. In order to support caregivers and increase the quality of their services, it seems necessary to design support systems that meet their requirements and expectations. For this purpose, it is necessary to collect comprehensive information and identify at risk caregivers, which according to the demographic distribution and cultural diversity of Iran, it is needful to pay attention to this issue that more studies should be done in all provinces. Considering the complementary areas of task of formal and informal caregivers, using the expertize and knowledge of nurses and formal caregivers can play important role in reducing the burden of care for family caregivers. These findings provide clear and basic information.

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Conflicts of interest

Nothing to declare.

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