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Family caregiver burden of elderly patients with cultural correlates: A systematic review

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REVIEW

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ABSTRACT

Background

The elderly eventually need caregiving, and the role for this has been more often than not fulfilled by family members. This can be attributed to numerous factors, from financial constraints to a lack of trust in others, or religious/cultural reasons. The purpose of this study is to review all current literature to find how cultural differences can impact caregiving with respect to the burden perceived by the caregiver.

Study design

Systematic review

Methods

Following PRISMA guidelines, a search was done using specific keywords such as “family”, “caregiver”, and “burden” from the databases of MEDLINE, Cochrane, and Pedro. The data items included a measure of burden with mention of scale used, stressors or factors along with their scales used, and cultural correlates of caregiver burden.

Results

Most of the family caregivers were elder daughters around the age range of 40-60 looking after their parents. The most common scale used to measure burden was the ZBI, followed by CBI, then CSI. The stressors that aggravated the burden were health-related disabilities of the elderly, and this was often measured using scales such as ADL or IADL. Eastern societies and even immigrants from the eastern nations, followed filial obligation and teachings such as Confucianism which stressed the importance of family care. These same individuals either experienced more burden or less burden, and the exact cause was not determined, but multiple factors were given including personal health of the caregiver, marriage status, and sense of obligation.

Conclusion

Obligation to the family is still present in much of the eastern hemisphere of the world, but it does not explain why different ethnicities that share similar beliefs and cultures experience different rates of burden. All the factors which affect burden have not been completely elucidated yet, and more research is required into determining how the different cultures are influenced by the multitude of factors related to caregiving.

Key Words

Family caregiver, Burden, Elderly, Caregiver burden scale.

Introduction

How is burden defined?

As an individual age, he/she becomes more dependent on assistance to continue to function optimally. This assistance may be in the form of technology, medical aid, or caregivers. Caregivers are individuals, such as social worker, family member, guardian, physician, or nurse who helps in the recognition, prevention, or treatment of a disease or disability[1]. The act of caring for the geriatric population can be a stress-inducing experience. This stress not only impairs the performance of the caregiver but also affects his/her health[2]. This can be gauged by measuring the ‘burden’ associated with caregiving. Specifically, the subjective burden can be defined as the caregiver experiencing symptoms of fatigue, stress, and reduced social interaction as a result of a poor assessment of the caregiving situation. This can potentially lead to impairment of the physical and mental health of the caregiver[3].

What are the different methodologies in assessing burden?

There are a handful of methods that have been used in order to measure burden. While burden can be measured qualitatively, the best methods employ the use of an instrument. Many instruments have been designed and refined over the course of the years, including but not limited to Montgomery's Burden Scale, Vitaliano's Screen for Caregiver Burden, Novak's Caregiver Burden Inventory, Kosberg and Cairl's Cost of Care Index, and the most commonly used Zarit's Burden Interview[4]. According to the literature, a total of 74 tools exist that measure caregiver burden[5]. Despite this, the concept of ‘caregiver burden’ has not been standardized, and a single proper definition of burden is not shared among the various studies. Also, the majority of the instruments utilized are in various languages and have only been used in different population sample sizes. This means the feasibility of most of these instruments should be properly tested.

What are the factors that elevate burden?

While the burden is a subjective experience by the caregiver, factors such as gender, level of education, common residence, number of hours spent caregiving, mental state, social circle, financial situation, and willingness as a caregiver can all influence caregiver burden[6]. Chronic illness in the recipient such as heart disease, cancer, or dementia can put more weight on one factor over the other[7-9].

How does culture influence caregiver burden?

Culture, which is synonymous with a collection of values, beliefs & principles that govern a social group, has been linked with caregiver burden. Existing literature has already established that variations such as kinship, shared residence, and social support influence the caregiver’s health[10-20]. The authors Kim and Lee proposed that the aforementioned factors were all subjective to cultural values. Further adding to the framework, the authors: Knight and Sayegh refined the model where the same cultural values were linked to caregiver burden[21-27].

While many studies have looked at caregiver burden with respect to cultural correlates, the focus of this study is exclusively on the impact of culture on the burden of family members who serve as caregivers. The review intends to determine just how primarily family caregivers differ from each other based on cultural differences and whether one form of culture is more advantageous with respect to reduced caregiver burden.

Methods

This review was carried out according to the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines. The timeframe of articles ranged from 2000 to 2022. The databases PubMed/Medline, Cochrane/EMBASE, and PEDro were searched. The search strategy involved using the specific keywords “Family”, “caregiver”, “burden”, “elderly”, and “cultural” in combination with the conjunctions "OR" and "AND". This gave a total of 415 studies. Pre-screening was done with the filters “Human studies only” and “English article only” and this eliminated 18 studies. Titles and abstracts were then reviewed by two independent assessors to include only those studies relevant to the topic. This amounted to the removal of 306 studies. An attempt was made to retrieve all remaining 91 studies; however, 6 were not retrieved. The remaining 85 were then reviewed for data items that fell under the inclusion criteria. A total of 50 studies were found violating the inclusion criteria i.e. did not have any data pertaining to burden scores, stress factors, or cultural correlates. In the end, only 35 studies were included in the final systematic review. (Figure 1).

Eligibility Criteria

The inclusion criteria for the studies were as follows

1. All studies involving elderly care by family members
2. All studies measuring the burden of care using any scale/inventory

The exclusion criteria for the studies were as follows

1. Any non-English articles
2. Non-human studies
3. Any study not mentioning cultural correlation with the burden of care

Data Collection

Mendeley web app was used to detect and import all search results into the Mendeley Reference Manager desktop application. All results were then exported to Endnote X7, where the titles and abstracts were reviewed. Data collected was then compiled into tables. The data extracted from the compiled studies and results produced in this systematic review provided a (deficient/sufficient) summary of the current literature relating to the burden of care of family members looking after the elderly with cultural correlates.

Data Items

- Study Author
- Age (mean)
- Gender Ratio (M/F)
- Inventories/Scales used to assess the burden
- Mean value of caregiver burden (with scale mentioned)
- Factors involved in elevating the burden
- Mean values of factors
- Findings of cultural correlation with the burden

Information Sources

1. PubMed/Medline (2000-2022)
2. Cochrane/EMBASE (2000-2022)
3. PEDro (2000-2022)

Search Strategy

Following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines [16], eligible articles were discovered via the above-mentioned databases using specific keyword combinations. The list below shows the keywords used in different arrangements:

1. Family AND caregiver AND burden
2. Elderly AND caregiver AND burden
3. Caregiver AND burden AND cultural
4. Elderly AND caregiver AND burden AND cultural
5. Family AND caregiver AND burden AND elderly AND cultural

Acronyms/Terminologies

BURDEN

1. CSI = Caregiver strain index: A 13-item instrument that was developed in the early 1980s to screen for caregiver strain after an elder patient was discharged from the hospital.

2. ZBI = Zarit burden interview: A 22-item instrument for measuring the perceived burden of providing family care. All items are evaluated on a 5-point Likert scale with a total score range of 0 to 88.

3. BAS = Burden Assessment Scale: A 19-item measure that covers both subjective and objective burden, 9 covering the former and 10 covering the latter.

4. CBI = Caregiver burden inventory: 24 questions divided into five dimensions: time-dependence, developmental, social, emotional, and physical burden. All have 5 items except for the last which has 4.

5. Perceived caregiver burden scale: A 31-item questionnaire with each item rated on a 4-point Likert scale.

6. FBIS = The Family Burden Interview Schedule (FBIS) is a 25-item semi-structured interview schedule to assess the burden of care placed on families of a patient with schizophrenia

7. CBS= Caregiver burden scale

8. SOC = Antonovsky's Sense of coherence (SOC) scale is used to measure personal coping capability. It consists of 13 items.

Scales used to determine factors that affect the burden

ADLs =Activities of daily living:

BI= Barthel Index

NPI = Cummings Neuropsychiatric Inventory

SPMSQ = Pfeiffer Short Portable Mental Status Questionnaire

1. MMSE= Mini-Mental State Examination
2. CDR= Clinical Dementia Rating
3. CES-D = Center for Epidemiology Studies Depression Scale
4. EuroQoL-VAS = European quality of life visual analog scale
5. GDS = Geriatric Depression Scale
6. HDS-R= Hasegawa Dementia Rating Scale
7. DBD=Dementia Behavioral Disturbance
8. C-SF36= the Chinese (HK) Version of the MOS 36-Item Short Form Health Survey
9. SSQ6= Six-item Social Support Questionnaire
10. CDR = Clinical Dementia Rating Scale
11. CIRS = Cumulative Illness Rating Scale
12. GH = General Health
13. CSS = Caregiver Satisfaction Scale
14. PES = Perceived Emotional Support Scale
15. CHQ = Chinese Health Questionnaire
16. BPRS = Brief Psychiatric Rating Scale
17. SWLS = Satisfaction with Life Scale
18. BDI = Beck’s Depression Index
19. CCI = Charlson Comorbidity Index
20. RSES = Rosenberg Self-Esteem Scale
21. CSDD = Cornell Scale for Depression in Neurocognitive Disorder;
22. SSR = Social Support Rating Scale

Cultural correlates

1. Kinship
2. Residence
3. Obligation
4. Reciprocity
5. TCFVQ= Traditional Chinese Family Values Questionnaire: An 18-item questionnaire that focuses on the core values of the traditional Chinese family, including gender division of labor, family taboos, marital philosophy, filial piety, and hierarchy.

Results

The majority of family caregivers were older children, followed by spouses. The age range was usually close to 50 or above. The majority of the caregivers were always female.

The most common scale used to measure burden was the Zarit Burden Inventory, followed by the Caregiver burden inventory, then the caregiver strain index. The factors that aggravated the burden were usually related to the impairment of the elderly, and this was often measured by ADL or IADL.

Regarding the cultural impact on the burden, filial piety, which is most often seen in eastern societies, was the most common reason for families to opt for caring for their elderly. However, this showed mixed results in changing burden i.e. in some cases it elevated it, in others, it decreased it depending upon the ethnicity (Table 1).

Discussion

Our results showed that the majority of family members who served as informal caregivers were mostly grown children who had taken the responsibility of looking after their elderly parents. Rarely the reason for was lack of proper health services or financial constraints, and most of the time it was due to a sense of responsibility from the children, despite it being an increasing burden on them. However, studies have shown that this filial obligation not only motivated the caregiver but helped him/her with coping and appraisal as well[28-32]. On the other hand, the practice can become so pervasive, that denying caregiving to the elderly would be considered taboo and unacceptable in that society[33]. When the same members of society immigrate, they have to conform to the social norms of the place they live e.g certain Chinese immigrants to America would begin to put their elderly in old homes rather than look after them themselves[34-38]. But not every immigrant acculturates to their new surroundings, and certain beliefs and cultures die hard.

Most of the caretakers were female. While the exact cause cannot be deduced, in societies with strong cultural influence, women are looked at as the primary caretaker of the family who nurses the elderly[39]. However, the trends are changing as more men are taking the role of caregiver. This is mostly because of the increased role of women in the workplace and less at home. Despite this, women often report more burden as compared to male caregivers [40-43]. This can be explained by the fact that women tend to cope with stressful situations arising from caregiving by relying on their emotions more, while men utilize more problem-oriented methods[44-47].

While the burden was increased in caregivers of patients with diseases, different illnesses brought about different levels of stress. Most articles covered physical impairments and how they affected caregiver burden[46]. Of those that covered mental impairments, the most commonly seen illnesses were Alzheimer’s or age-related dementia. Symptoms arising from any of the aforementioned diseases were indicative of increased caregiver burden. This is supported by a meta-analysis comprising 228 studies that found neuropsychiatric symptoms as the best predictors of caregiver burden[47-51]. In particular, symptoms such as delusions, depression, and apathy were most notorious for agitating caregivers. Dementia in care recipients alone has been attributed to reduced quality of life in caregivers.

Regarding cultural differences in various ethnicities, a study concluded that ethnicity itself does not contribute to the burden directly. In the same study, which was conducted in Trinidad, while caregiver burden was significantly associated with the care recipient belonging to a minority group, the minority groups themselves were not of East Indian or African descent. Instead, they were white Caucasians and were experiencing more burden than the reported burden experienced by African caregivers. Normally whites experience less burden compared to all other ethnicities, but this study proved that it was actually the individual who was part of a ‘minority’ that experienced more burden and not the ethnicity itself [52-57].

Conclusion

While cultural differences are acknowledged to influence the burden of the elderly by family caregivers until now a proper scale has not been developed looking into this factor alone. Moreover, in areas with similar or overlapping cultures and beliefs (e.g China, Thailand, Taiwan) there still exists a difference in the burden of care despite the common filial obligation practiced in this region. Further research is necessary to isolate all the confounding factors that affect the burden of care score.

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Figures and Tables

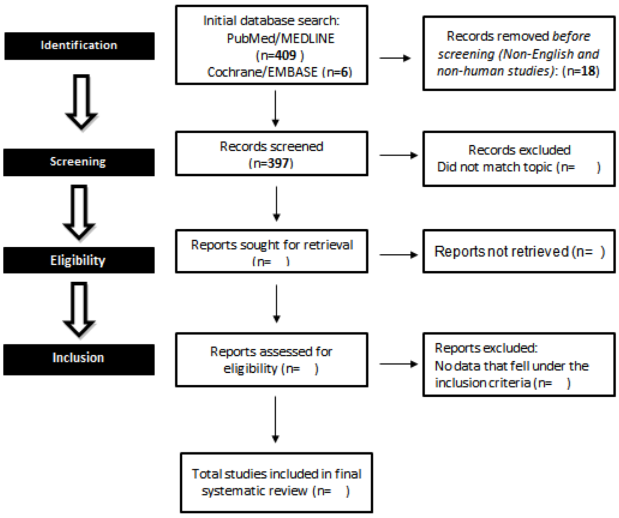

Figure 1: PRISMA Flowchart showing search strategy

Table 1: Synthesis of data from the included studies in this review

Study ID	**Sample size**	**Average Age(years)**	**Gender Ratio (M/F)**	**Caregiver burden mean score (unit)**	**Factors elevating burden**	**Cultural correlates**
del-Pino-Casado et al., 2014	n=208	59	14.9% / 85.1%	CSI= **6.27**	Amount of care provided= **59.6 hours per week**	A significant negative relationship between perceived social support and the burden of care
				46.2% experienced a burden	ADLs =**7.7**	
					BI = **38.3**	
					NPI = **7.5**	
					SPMSQ = **5.1**	
Garlos et al., 2010	n=179	62±14	22% / 78%	ZBI= **7.12** (SD=7.2)	Physical discomfort **(57%)**	-

					More help with tasks needed **(88%)** More emotional support needed **(97%)**	
Tsai et al., 2021	n=328	37 ± 7.0	61% / 39%	ZBI= **26.65** (SD=18.12)	MMSE = **17.78** IADL = **4.33** CDR = **1.16** NPI (Total) = **4.45**	-
Sabzwari et al., 2016	n=350	47.23 ± 15.5	31.1% / 68.9%	Perceived Care Burden Scale = **50.3%**	IADLs with a significant burden: help with shopping, managing money, preparing meals, and ensuring hygiene (P < 0.05) Financial constraints had the strongest correlation (**0.79**)	Most care providers were women, as is the norm in the Pakistani setting, but males experienced more burden.
Tro et al., 2022	n=299	35.58 ± 6.7	100% female	ZBI (unmarried)=**31.12** (p=0.003) ZBI (Childless)=**31.66** (p=0.013)	Chinese proficiency was negatively associated with severity and guilt	
Flores et al., 2021	n= 200	56.1 ± 8.2	22%/78%	Perceived Social stress = **4.1 ± 2.4**	CES-D = **4.8** NPI = **2.7 ± 2.7** ADL = **3.6 ± 2.5** MMSE = 58.5	Caregivers feel an increased sense of obligation due to cultural expectations, *Familismo* (emphasis on the obligation to the family)
Ryuno et al., 2020	n=23	66.9 ± 11.0	30.4%/69.6%	ZBI = 8.8 ± 6.8	PSQI = **5.2 ± 3.6** WHO-5 = **13.8 ± 3.5** GDI = **4.5 ± 3.5** Total sleep time, total time in bed, PSQI, frequency of going outdoors by CRs all significantly correlated with ZBI (p < 0.05)	
Cho et al., 2020	n=234 (USA), n=304(Japan)	-	-	ZBI(USA)=**18.26 (±12.91)**, ZBI(Japan)= **26.37 (±17.31)**	ADL=**5.99/5.53** MMSE=**17.12/12.45** In USA agreeableness and conscientiousness was (-) associated with ZBI, neuroticism, and a number of diseases were (+) associated with ZBI. In JAPAN, ADL, openness, and agreeableness were (-) associated with ZBI	The study attributes the results of Japan to filial piety and those of the USA to personal choice.
Watanabe et al., 2019	n=313	22-85 (Median= 55)	22.3%/77.7%	CBI 41.7% experienced a burden	CBI was significantly related to the caregiver's own health problems, poor sleep	The role of older care is mainly fulfilled by female family members in the traditional Thai culture.

					quality, daily hours providing care ≥ eight hours, care-recipient's low ADL level, and care-recipient's low cognition level	
Rocha-Balcázar et al., 2018	n=111	48.1 ± 15.2	22.8%/77.2%	ZBI	ADL = **84.6**	-
				39.60%	IADL = **9.1**	
				experienced burden	GDS = **10.6**	
					MMSE = **19.3**	
					EuroQoL-VAS =**64.6**	
					Depression was only associated significantly with caregiver burden	
Win et al., 2017	n= 458	53.6 ± 13.5	32.7%/67.3%	ZBI =	NPI-Q severity =**5.6 (SD 5)**	Adult children may be forced into the caregiving role as there are social expectations to care for elderly family members (filial piety)
				25 (SD 17.4)	NPI-Q distress =**5.8 (SD 7.2)**	
					The majority of caregivers (76.6%) resided with the care recipient	
					The majority of caregivers were adult children (85.9%)	
Ajay et al., 2017	n= 140	45.4± 15.7	10%/90%	ZBI = **21.2 (SD 12.9)**	ZBI scores were higher in those caregivers looking after older persons with multiple impairments Significant a	The family is the traditional social institution for the care of older persons in India
Akpinar et al., 2011	n= 192	Male = 74.26 ± 8.27	23%/67%	CBI (Male)= **44.63 ± 22.39**	MMSE= **10.65 /10.48**	The lower score on the social burden subscale might be a result of strong family bonds and the sensibility of caregiving for the elderly at home in Turkish society
		Female=75.83 ± 8.9		CBI(Female)= **54.63 ± 21.15**	NPI= **37.76/ 44.12**	-
Arai et al., 2000	N=70	59.5± 13.7	11.4%/ 88.6%	ZBI = **34.9 (SD 17.9)**	BI=**13**	In Japan, there is a cultural mind-set where the elderly have difficulty obtaining public services
					HDS-R=**15.5**	
					DBD=0	
Baboolal et al., 2018	N=75	57.3± 15.2	18.7%/ 81.3%	ZBI=**24.3**	MMSE=13	The burden was associated with belonging to a minority ethnic group (Trinidadian)
				(SD 14.5)	ZBI was strongly associated with the caregiver's poor health, and not having time for him/herself, poor social life	
Chan et al., 2011	N=101	73	33.7%/66.3%	CBI= **49.76 (SD 5.36)**	LSNS=**24.02**	Caregivers with high recognition of family values were associated with a higher level of caregiver burden
					KMSS=**14.80**	
					Caregiver perceived health=**2.33**	
					ADL=**14.31**	

					IADL=**14.84** TCFVQ=**43.37**	
Cheng et al., 2013	N=142	58.85 ± 13.18	27%/73%	ZBI = **24.46 (SD 14.83)**	Psychosis, behavior problems, and mood disturbance were significantly associated with caregiver burden and depression	Chinese caregivers in Hong Kong and Taiwan were less troubled by apathy and depression
Chien et al., 2007	N=203	45	44.8%/ 55.2%	FBIS = **29.02**	FAD=**18.89** C-SF36=**35.14** SSQ6=**2.28** FBIS was (+) correlated with their age; it was (-) correlated with their monthly household income and number of family members living with the patient	Results pointed out that the Chinese caregivers with traditional Chinese religions such as Confucianism and Buddhism reported higher levels of a burden than those who were Christians or Catholic
Chindaprasirt et al., 2014	N=150	48 (median)	18.67%/81.33%	ZBI = **9.2±12.9** 37% experienced a burden	High burdens were connected with a single caregiver, sibling relationship with the patient, migraines, and cancer types of the patients	Taking care of spouses and parents is a burden taken willingly and seen as a duty in Thailand.
Choo et al., 2003	N=70	52.3 ± 12.8	30%/70%	ZBI = **35.4 (SD=15.08)**	Lack of social support increased the burden	A significant association between ethnicity and burden Malaysians had a lower burden compared to Chinese or Indians.
Cova et al., 2018	N=50	58±14.9	38%/62%	ZBI = **8.7 ± 3.9**	NPI-Q = **42.7** CNA=**5.2** MMSE=**16.2** CDR=**1** ADL=**1** IADL=**4** CIRS=**0.5**	
Gok Metin et al., 2019	N=131	53.73 ± 13	29.8%/ 70.2%	ZBI = **37.59 ± 18.20**	EFS = **8.93 ± 2.34** EFS was strongly associated with ZBI	The increasing influence of western culture is reducing filial responsibilities
Guo et al., 2019	N=393	47	35.88% / 64.12%	High filial obligation gave low CBI (mean values not given)	There was a difference between subjective and objective burden; the latter was (+) associated with the filial obligation	Programs that celebrate the cultural heritage of Chinese immigrants can increase filial obligation and reduce caregiver burden.
Han et al., 2017	N=164	55.97 (SD 14.2)	31%/69%	CSI = **7.35(SD 2.9)**	BI= 40.12 CES-D=9.71	Chinese cultural values alleviate the caregiver's burden
Harwood et al., 2000	N=40	60.9 (SD 13.9)	30%/70%	CBS = **32.7 (SD 9.0)**	CSS = 18.9 GH = 61.8 PES = 26.3	Acculturation, measured by length of stay in the USA, did not affect caregiver appraisal
Hou et al., 2008	N=126	-	38.1%/ 61.9%	CBI = **25.87**	CHQ < 4 (72.2%) BPRS scores significantly associated with the burden	-

Jeong et al., 2015	N=238	52.41 ± 11.63	30%/70%	CBS = **2.21±0.70**	The Burden was significantly associated with QoL	In Korea, family feels obligated to provide care for the elderly and at the same time are reluctant to express their personal emotions in doing so
Kowalska et al., 2017	N=58	54.7 ± 12.6	22%/78%	CBS = **2.63 ± 0.61**	BDI = **12.9 ± 7.6** SWLS = **19.9 ± 6.4**	Because the western family system is becoming dominant in Poland, there is more burden of caregiving for elderly
Li et al., 2013	N=65	59.7± 13.3	27.7%/ 72.3%	ZBI = (no mean value given)	Expressed emotion EE was positively correlated with the burden	The low support of the negative attitude toward the illness was an expression of the Chinese cultural beliefs of 'tian (heaven) ming (destiny)', which means heaven decides for the individual so it's pointless to fight it
Luchsinger et al., 2015	N=139	59.3 ± 10.4	100% female	ZBI = **43.23 ± 18.63**	CCI = **1.62** GDS = **11.27** Self-reported caregiver depression = 23 Higher dementia severity was associated with a higher caregiver burden	Acculturation was not associated with caregiver burden or depression
Papastavrou et al., 2014	N=76	-	25%/75%	ZBI = **43.32 (SD 15.23)**	CES-D = **19.25** QoL = **30.89** ADL = **2.27**	Family factor had a high rating, suggesting people relate more with traditional values and give care in a collectivistic rather than
Sousa et al., 2016	146 (Spain) / 128 (Brazil)	60.5 versus 58.6	77.4% versus 78.1 % women	ZBI = **19.6 (13.2)** *Versus* **29.7 (17.7)**		In Brazil, a higher burden was associated with those who did not attend day care In Spain, it was the reverse
Stanley et al., 2017	N=75	49	62.6%/ 37.4%	ZBI = 82.5	QoL = 92.9 A high perceived burden was associated with lower QOL	In India due to a lack of decentralization of medical services, families resort to faith healers and charlatans. Otherwise, the belief is the onus of care rests on the family.
Yang et al., 2012	N=1144	44.3± 11.5	40.21%/ 59.79%	ZBI = 27.3, SD 15.0	SOC was higher the more years spent in caregiving High ZBI was associated with low QoL	Confucianism spirit is still practiced, but this still leads to an increased burden of care
Young et al., 2017	N=57	65.5 (12.9)	56.1%/ 43.9%	ZBI = 31.04 (19.54)	QoL = 3.34 GDS = 5.57 RSES = 26.48 CSDD = 8.64	Chinese people with neurodegenerative disorders are considered those who fail to conform to the five cardinal relations and duties established by Confucianism

						and are seen as incompetent members of society.
Zeng et al., 2017	N=231(Ghangzou) /	45.46 (13.18) versus	49.8/ 50.2 versus	FBIS =17.49	QoL= 74.59	More social support is seen in Hong kong
	132 (Hong Kong)	49.45 (13.71)	35.6/ 64.4		SSRS = 40.35	
					Guangzhou had significantly higher levels of a burden than did family caregivers in Hong Kong	

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