

Access this article online

Quick Response Code:



Website:

www.jfcmonline.com

DOI:

10.4103/jfcm.JFCM_117_16

The burden perceived by informal caregivers of the elderly in Saudi Arabia

Sulaiman A. Alshammari, Abdullah A. Alzahrani, Khaled A. Alabduljabbar, Abdulaziz A. Aldaghri, Yazeed A. Alhusainy, Mohammed A. Khan, Rakan A. Alshuwaier, Ismail N. Kariz

Abstract:

OBJECTIVES: The objective of this study was to discover the characteristics of informal caregivers of elderly patients; to determine the socioeconomic, psychological, and physical consequences facing informal caregivers; and to measure their burdens and needs.

MATERIALS AND METHODS: This study was a cross-sectional survey of informal caregivers of elderly patients. Participants were recruited from different hospitals and primary care clinics in Riyadh, Saudi Arabia. For an intended sample size of 384 caregivers, a multistage sampling was used. A self-administered questionnaire was used to collect data. Data analysis included student's *t*-test and ANOVA to test for statistical significance.

RESULTS: The study included 315 caregivers of elderly patients. Over half of the elderly patients were female (55.9%) and over 70 years old (65.7%); about 31% had chronic diseases or disabilities, which represented the majority of health problems reported by the elderly population. Most of the caregivers were family members (87.9%), young (43.8%), female (52.7%), unemployed (54.6%), and unmarried (58.1%). Most caregivers suffered from musculoskeletal problems (78.1%). The mean Zarit Burden Interview score was 31.3, which indicated a moderate burden. More than half of caregivers requested blood pressure (55.6%) and blood sugar measuring devices (53%). Three quarters (74.9%) of the caregivers wanted educational training to cope with emergencies. Most caregivers expressed a need for frequent healthcare for themselves (58.4%) and a home health visit service (72.9%) to support them in the care of their elderly.

CONCLUSIONS AND RECOMMENDATIONS: Mobilization of resources in locations where these carers of the elderly live are greatly needed. In addition, health authorities should provide devices and essential training to manage the common problems and emergencies that informal caregivers have to deal with. Moreover, caregivers need follow-up supervision by a home visit team. Further studies are required to guide the implementation of the above advice.

Keywords:

Burden, caregiver, elderly, Saudi Arabia

Research Chair of Health Education and Health Promotion, Department of Family Community Medicine, King Saud University, Riyadh, Saudi Arabia

Address for correspondence:

Prof. Sulaiman Abdullah Alshammari, Department of Family and Community Medicine, College of Medicine, King Saud University, P. O. Box 2925, Riyadh 11461, Saudi Arabia. E-mail: sulaiman@ksu.edu.sa

Introduction

Many studies have investigated the effect of the burden on the physical, psychological, and social status of the caregiver. However, some researchers have sought solutions to lessen the caregiver's burden.^[1]

Abu Kamel *et al.* (2010) reviewed 19 studies of the experiences and needs of caregivers for stroke patients. They found that fatigue, sleep alteration, exhaustion, and pain were the most often documented physical complaints of caregivers.^[2] Belasco *et al.* demonstrated that the emotional status of caregivers, their vitality, and mental health were the most affected.^[3] Denno *et al.*

This is an open access article distributed under the terms of the Creative Commons Attribution-NonCommercial-ShareAlike 3.0 License, which allows others to remix, tweak, and build upon the work non-commercially, as long as the author is credited and the new creations are licensed under the identical terms.

For reprints contact: reprints@medknow.com

How to cite this article: Alshammari SA, Alzahrani AA, Alabduljabbar KA, Aldaghri AA, Alhusainy YA, Khan MA, *et al.* The burden perceived by informal caregivers of the elderly in Saudi Arabia. *J Fam Community Med* 2017;24:145-50.

concluded that as the burdens of caregivers increased, the more likely they were to experience anxiety and depression.^[4] Abu Kamel *et al.* (2009) ascertained that caregivers felt socially isolated by their role.^[2] Salama noted that caregivers were most commonly the wives of the elderly patients. With little or no social and financial support, these caregivers were more likely to be burdened unduly.^[5] Faison *et al.* (1999) found a positive correlation between the number of carers' activities and their burden.^[6] Brinda *et al.* showed that a heavier burden was associated with patients who had had a stroke, Parkinson's disease, disabilities, insomnia, and incontinence and that a lot of time was spent on assisting dependent, older people in daily activities, and supervision.^[7] Likewise, Gratao *et al.* observed a significant relationship between a caregiver's burden and the recipient's stage of dementia.^[8] Moreover, Shankar *et al.* found that caregivers perceived the burden as greater if they were young, were a spouse, had depressive symptoms, had difficulty managing the symptoms of their recipients, or had limited finances at the end of the month. The caregiver's burden was strongly associated with the care recipient's distressing neuropsychiatric symptoms, delirium, and functional deficits in the basic activities of daily living.^[9] In addition, Miura *et al.* highlighted a significant relationship between the recipient's mental health status and the burden perceived by the caregiver.^[10] Concerned about the effect of cultural factors, del-Pino-Casado *et al.* concluded that subjective burdens (namely, distress and embarrassment) were negatively associated with perceived social support and reciprocity. Evidence in literature indicates that cultural factors influence the caregiver's burden, with one study reporting that cultural factors explained 29% of the variance in burden.^[11]

Some studies have addressed this issue by seeking solutions to lessen the burden on caregivers. Smits *et al.* studied the effect of combined intervention programs on people with dementia and their carers. They concluded that these programs helped improve some aspects of functioning of both individuals, particularly regarding mental health. However, the effects on cognitive and physical functioning, behavioral problems, and the survival of the people with dementia were modest and inconsistent.^[12] Al-Khashan *et al.* asserted that home services that provide additional healthcare support to patients improved the self-confidence of their caregivers. Although these frequent home visits increased caregiver satisfaction, the additional help in the areas of physiotherapy, vocational therapy, and social services was inadequate.^[13] Similarly, Faison *et al.* (1999) suggested that community nursing services should be employed to reduce the burden on the informal caregiver.^[6]

The present study is one of the few studies conducted in the Arab world concerning the issue of caregivers' burdens and needs. It sheds light on the role of informal carers of elderly people in Saudi Arabia, whose numbers increase every year. The results will provide a basis for developing a program to teach and support this group of people in their arduous work.

Materials and Methods

This was an observational, quantitative, cross-sectional study. The study used a stratified, multistage sampling technique and was conducted in several hospitals in Riyadh over 3 weeks. The Ministry of Health facilities included King Saud Medical City and primary care clinics, and the non-Ministry of Health facilities included King Khalid University Hospital and the remaining hospitals.

The study was conducted at King Khalid University Hospital, King Saud Medical City, Dallah Hospital, King Salman Hospital, and several primary care clinics selected randomly in Riyadh from November 2014 to April 2015.

Its aim was to investigate the burden on informal caregivers. Therefore, it included randomly selected informal caregivers (aged 18 years and older) of both male and female elderly patients (aged 60 years and older). Formal caregivers, such as nurses, were excluded from the study. It was conducted in Riyadh City, with a population of 5.25 million people, 262,500 of whom are elderly.^[14] The elderly form 5% of the total population in Saudi Arabia. Considering a confidence level of 95% and an error margin of 5%, using an electronic sample size calculator, we estimated that a sample size of 384 elderly people was needed.^[15]

A self-administered questionnaire was designed for data collection. It was composed of two parts: (1) questions related to the elderly recipient of care and (2) questions related to the informal caregiver. The part that dealt with the elderly gathered information on sociodemographic characteristics and health problems. That on the informal caregiver elicited information on sociodemographic characteristics, psychological status, and physical health. The researchers also developed a ten-question, yes-no questionnaire to measure the socioeconomic, psychological, and physical consequences of the caregiver's functions. The questionnaire was evaluated by the consultants who assessed its validity. To ensure its reliability, the questionnaire was used to conduct a pilot study. Before data collection, the self-administered questionnaire was distributed to twenty informal caregivers to determine its feasibility and intelligibility and assess the required time for completion.

The Zarit Burden Interview (ZBI) was used to measure caregiver’s burden.^[16-18] The ZBI is a 22-item, self-administered questionnaire that is widely used by many agencies to measure the burden of a carer for an elderly person or a relative. A 5-point Likert scale, ranging from 0, representing “never,” to 4, representing “nearly always,” was used to assess the ZBI. The sum of the item scores results in a global score ranging from 0 to 88, with higher scores indicating a greater burden as perceived by providers of family care. The ZBI cutoff scores that were used to divide the severity of the burden into four groups were 0–20, no or little burden; 21–40, little to moderate burden; 41–60, moderate to severe burden; and 61–88, severe burden.^[19] We did not find any study in Saudi Arabia or the Arabian gulf countries which assessed informal caregivers of the elderly by ZBI. Permission was taken from the owner of the copyright to use the ZBI scale which was then translated into Arabic by two investigators and retranslated into English by two independent English speakers and the necessary modifications made. The version was piloted on twenty informal caregivers for feasibility and clarity.

All participants were given a consent form which they signed. The informed consent form was clear and indicated the purpose of the study, the participant criteria, the rights of participants regarding participation in the study, and how the data would be used. No incentives or rewards were given to the participants, and their anonymity and confidentiality were guaranteed.

The statistical analyses were performed using SPSS version22, IBM, USA.^[20] The results were presented as percentages, means, *P* values, and standard deviations. Student’s *t*-tests and ANOVA were used for data analysis.

The Ethics Review Committee of the College of Medicine, King Saud University, Riyadh, approved this study (designated as B6) on December 1, 2014.

Results

Of the 384 recipients of the questionnaire, 82% responded, and therefore, 315 elderly individuals were evaluated.

The characteristics of the elderly are shown in Table 1. The study included 176 women (55.9%) and 139 men (44.1%). Elderly patients between 70 and 79 years of age represented the largest age category (35.9%). Seventy-five percent of the participants (75.0%) perceived themselves to be in either good or excellent health. The majority (72.2%) of health problems of these elderly individuals included chronic problems or disabilities, cognitive impairment, and senility.

Table 2 shows the characteristics of the informal caregivers. Of the 315 caregivers, 52.7% were female,

58.1% were single, and 54.6% did not have paid work. In the majority of cases (69.8%), the primary caregivers of the elderly were sons or daughters. There were more daughters than sons as caregivers. Many caregivers (43.8%) were young, between the ages of 18 and 27 years, and 88.3% had high school education or higher. Most of them (94.6%) felt that their general health was either good or excellent, and more than half (63.2%) lived in a villa.

Figure 1 shows the social, economic, psychological, and physical issues of informal caregivers. Most of them (78.1%) suffered from musculoskeletal problems, including bone, joint, or muscle pain. In addition, nearly three quarters of them had work-related problems (74.9%) and depression or mood swings (69.2%). Besides, 14.3% reported having financial problems.

Table 1: Characteristics of the elderly participants (n=315)

Variables	Categories	Frequency (%)
Gender	Female	176 (55.9)
	Male	139 (44.1)
Age (years)	60-<70	108 (34.3)
	70-<80	113 (35.9)
	≥ 80	94 (29.8)
Health perception	Excellent	38 (12.0)
	Good	198 (62.9)
	Poor	56 (17.8)
	I cannot say	23 (7.3)
Health problem	Temporary disease, disability of severe complaints with the prospect of complete recovery	80 (25.4)
	Chronic disease or disability	99 (31.4)
	Dementia or memory problems	33 (10.5)
	Mental or psychiatric problems	11 (3.5)
	Problems due to aging	89 (28.3)
	Other	3 (0.9)
	Total	

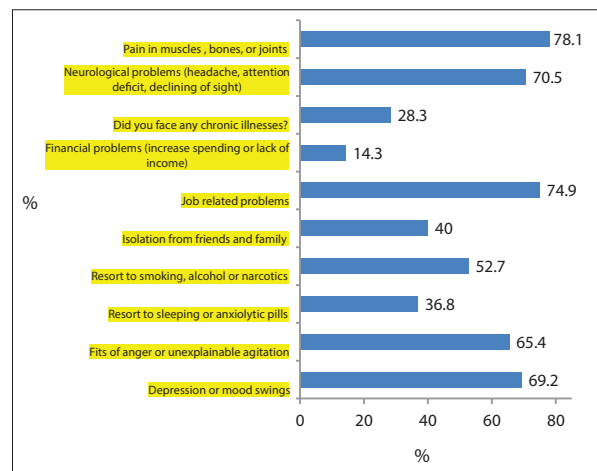


Figure 1: Social, economic, psychological and physical problems faced by the caregivers

Table 2: Characteristics of the informal caregivers versus Zarit Burden Interview mean scores (n=315)

Variables	Categories	N (%)	Mean±SD	p-value
Gender caregiver	Male	149 (47.3)	29.6±16.5	0.670
	Female	166 (52.7)	32.7±16.8	
Age caregiver (years)	18-27	138 (43.8)	28.5±15.0	0.091
	28-37	84 (26.6)	34.7±17.3	
	38-47	43 (13.7)	31.3±16.8	
	48-57	40 (12.7)	33.3±17.6	
	>58	10 (3.2)	32.5±24.9	
Educational level	Below high school	37 (11.7)	38.4±16.8	0.092
	High school and higher	278 (88.3)	39.5±17.1	
Type of housing	Villa	199 (63.2)	30.6±17.5	0.799
	Floor	48 (15.2)	32.5±15.6	
	Apartment	66 (21.0)	32.3±15.1	
	Castle	1 (0.3)	22.0±0	
	Traditional house	1 (0.3)	43.0±0	
Marital status	Married	132 (41.9)	31.5±17.7	0.852
	Single	183 (58.1)	31.1±16.0	
Do you have paid work/are you an employee?	No	172 (54.6)	29.7±15.9	0.151
	Yes, I work full time	113 (35.9)	32.7±16.8	
	Yes, I work part time	30 (9.5)	35.0±20.0	
Health perception	Excellent	183 (58.1)	33.2±16.5	0.0001
	Good	115 (36.5)	53.7±18.9	
	Poor	8 (2.5)	47.7±17.4	
	I can't say	9 (2.9)	9±2.9	
What is the relationship between you and the elder	Son/daughter	220 (69.8)	31.2±16.6	0.995
	Grandson/granddaughter	57 (18.1)	31.2±15.8	
	Other	38 (12.1)	31.5±18.7	
Total		315 (100)		

SD = Standard deviation

Figure 2 shows the burden on informal carers of the elderly; the ZBI was used to determine the degree of burden. We observed that respondents reported a varied level of burden, with the majority scoring between 21 and 40 which falls under the category of little to moderate burden (42.9%) while 30.8% showed no to little burden. The mean ZBI score was 31.3 (moderate burden).

Figure 3 shows that the informal caregivers asked for medical devices to help in the care of the elderly in their charge. They felt that they were in need of blood pressure (55.6%) and blood sugar measuring devices (53%). Most of the caregivers desired educational programs and short training courses, including instruction to help them to deal with emergency situations (74.9%) or to care for wounds (37.8) as shown in Figure 4.

It is apparent from Figure 5 that over half of the caregivers required frequent healthcare for themselves (58.4%). A regular home health care visit was desired by 72.9% of caregivers to ensure that they were in good health to

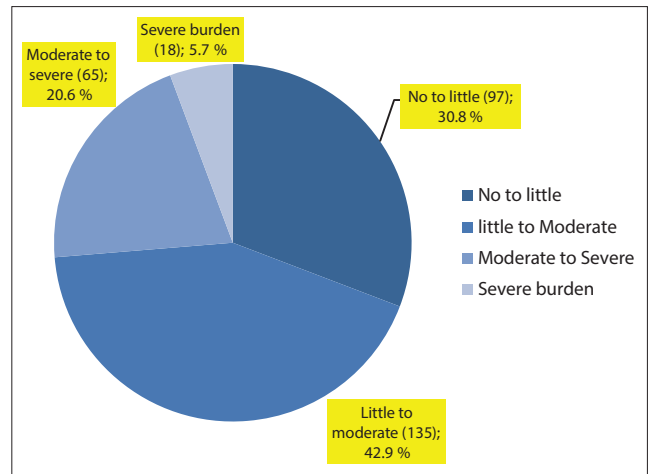


Figure 2: Burden felt by the informal caregivers while taking care for their elderly using Zarit Burden Interview

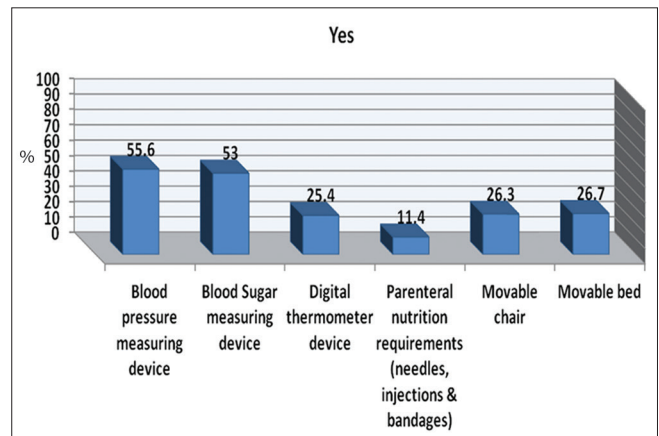


Figure 3: Informal caregivers' demand for medical devices to take care of their elderly at home

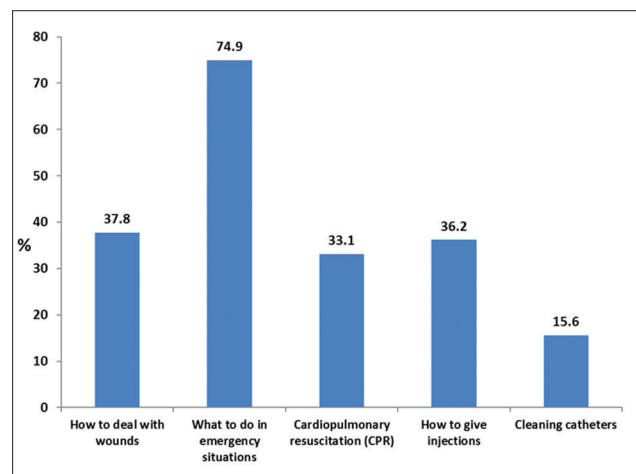


Figure 4: Educational programs and courses were desired by caregivers to help them take care of their elderly at home. NB: Response categories are not mutually exclusive

care for their elderly patients. Nearly a quarter (24.4%) of caregivers reported the need for financial support.

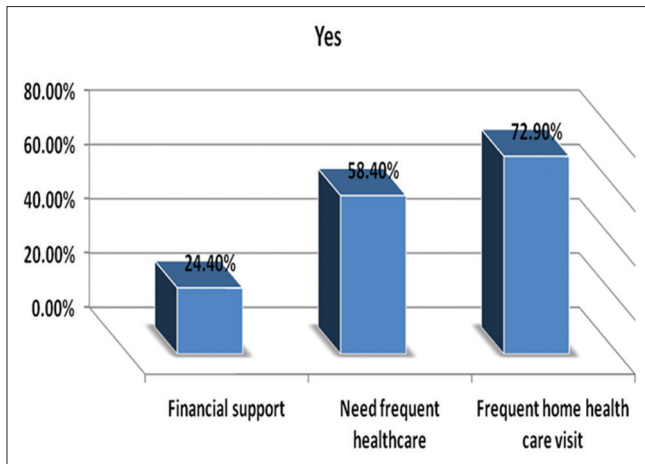


Figure 5: Percentage of the caregivers who needed frequent healthcare for themselves, frequent home healthcare visit service to aid with care and financial support

One-way ANOVA was used to determine the relationship between caregiver's burden, their age and gender, and the health problems of their elderly recipients; however, the results showed no significant differences.

Discussion

The caregivers felt that they needed blood pressure (55.6%) and blood sugar measuring devices (53%). These requests are because of the high prevalence of hypertension and diabetes in the elderly population in Saudi Arabia.^[21,22]

With increases in health care expenses, particularly for inpatient care, it must be emphasized that care for the elderly is best offered from within the community. Family members increasingly find themselves supporting and caring for their elderly or physically challenged relatives at home.^[23]

Over half of the informal caregivers were female (52.7%), and many were between the ages of 18 and 27 years (43.8%). Moreover, the majority of caregivers were single (58.1%) and unemployed (54.6%). These results are consistent with those from other international studies on caregivers.^[5,8,24]

The current study demonstrated that most (78.1%) informal caregivers suffered from musculoskeletal problems. This is consistent with the results of a previous study.^[25] The ZBI scale used to measure the caregiver burden for elderly patients showed that many individuals in our sample (42.9%) scored in the little to moderate burden level (21–40). A study published in 2012 from rural lower Egypt^[5] reported a ZBI score of 35 ± 15 , representing a moderate burden level.

The present study showed that the majority of elderly people in our sample were over 70 years old (65.7%),

and more than half were female (55.9%). Chronic diseases and disability accounted for 31.4% of the health problems of the elderly. Other studies reported similar characteristics for elderly people who required the need for carers; however, unlike our study, those studies reported that the elderly patients in their study were aged 65 and older. Other studies have also reported that the majority of the elderly included were female,^[26] and that they typically suffered from chronic diseases and disabilities.^[6]

Conclusions

We found that elderly patients were more typically female; most were over 70-year-old and suffered from chronic diseases or disabilities. However, most of the caregivers were single females without an occupation. Most of the caregivers were 18–27-year-old, and most complained of bone, joint, and muscle pain. The mean ZBI score of the caregivers was 31.3, which indicated a moderate burden. The majority of caregivers requested blood pressure and blood sugar measuring devices. They also asked for educational training, particularly for emergencies. In addition, the majority of caregivers expressed a desire for frequent medical care for themselves and a home health visiting service to support them in caring for their elderly patients.

Limitation of the study

Our study was limited to the capital city, Riyadh, in the Kingdom of Saudi Arabia. Furthermore, we used stratified, multistage sampling and conducted the study in different hospitals and primary clinics over a period of 3 weeks. These hospitals included the King Saud Medical City, primary care clinics, King Khalid University Hospital, and Dallah Hospital and the data collection was self-funded.

Recommendations

We suggest the skills of informal caregivers should be improved through planned educational courses. In addition, the physical burden of these informal caregivers could be reduced by providing them with mobile furniture, such as mobility chairs and beds. Moreover, this burden could be reduced by improving communication with health-care providers through social networks, such as WhatsApp and Twitter, telephone calls, and E-mails. Respite care services, for a few hours or a few days, may also relieve stress, restore energy, and promote balance in the caregiver's life and thus enable them to live more comfortably in their environment. Finally, we recommend further studies of the burdens on caregivers for elderly individuals. We advise future researchers to collect samples from more than one city, increase the number of hospitals, and collect data for longer periods.

Acknowledgment

We would like to thank all the informal caregivers who participated in the study. Thanks to King Khaled University Hospital, King Saud Medical City, Dallah Hospital, King Salman Hospital and different primary care clinics for allowing us to collect the participants' data. Special thanks to the research chair of health education and health promotion, Deanship of Scientific Research, King Saud University, Riyadh, Saudi Arabia. Also we are grateful to Mr. Zarit for his kind permission to use his burden scale.

Financial support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

References

- Garcés J, Carretero S, Ródenas F, Alemán C. A review of programs to alleviate the burden of informal caregivers of dependent persons. *Arch Gerontol Geriatr* 2010;50:254-9.
- Abu Kamel A, Bond E, Froelicher ES. Stroke patients' caregivers: Their experiences and needs: A qualitative literature review (review articles). *Jordan Med J* 2010;43:4.
- Belasco A, Barbosa D, Bettencourt AR, Diccini S, Sesso R. Quality of life of family caregivers of elderly patients on hemodialysis and peritoneal dialysis. *Am J Kidney Dis* 2006;48:955-63.
- Denno MS, Gillard PJ, Graham GD, DiBonaventura MD, Goren A, Varon SF, *et al.* Anxiety and depression associated with caregiver burden in caregivers of stroke survivors with spasticity. *Arch Phys Med Rehabil* 2013;94:1731-6.
- Salama R. Caregiver burden from caring for impaired elderly: A cross-sectional study in rural Lower Egypt. *Italian J Public Health* 2012;9:4-10.
- Faison KJ, Faria SH, Frank D. Caregivers of chronically ill elderly: Perceived burden. *J Community Health Nurs* 1999;16:243-53.
- Brinda EM, Rajkumar AP, Enemark U, Attermann J, Jacob KS. Cost and burden of informal caregiving of dependent older people in a rural Indian community. *BMC Health Serv Res* 2014;14:207.
- Gratao AC, do Vale Fde A, Roriz-Cruz M, Haas VJ, Lange C, Talmelli LF, *et al.* The demands of family caregivers of elderly individuals with dementia. *Rev Esc Enferm USP* 2010;44:873-80.
- Shankar KN, Hirschman KB, Hanlon AL, Naylor MD. Burden in caregivers of cognitively impaired elderly adults at time of hospitalization: A cross-sectional analysis. *J Am Geriatr Soc* 2014;62:276-84.
- Miura H, Arai Y, Yamasaki K. Feelings of burden and health-related quality of life among family caregivers looking after the impaired elderly. *Psychiatry Clin Neurosci* 2005;59:551-5.
- del-Pino-Casado R, Millán-Cobo MD, Palomino-Moral PA, Frías-Osuna A. Cultural correlates of burden in primary caregivers of older relatives: A cross-sectional study. *J Nurs Scholarsh* 2014;46:176-86.
- Smits CH, de Lange J, Dröes RM, Meiland F, Vernooij-Dassen M, Pot AM. Effects of combined intervention programmes for people with dementia living at home and their caregivers: A systematic review. *Int J Geriatr Psychiatry* 2007;22:1181-93.
- Al-Khashan H, Mishriky A, Selim M, El Sheikh A, BinSaeed AA. Home caregivers' satisfaction with the services provided by Riyadh Military Hospital's home support program. *Ann Saudi Med* 2011;31:591-7.
- Ashwan MS, Salam AA, Mouselhy MA. Population growth, structure and distribution in Saudi Arabia. *Int J Humanit Soc Sci* 2012;1:33-46.
- Available from: <https://www.surveymonkey.com/mp/sample-size-calculator>. [Last accessed on 2017 Mar 18].
- Zarit SH, Zarit JM. The Memory and Behavior Problems Checklist and the Burden Interview. Pennsylvania, USA: Gerontology Center, the Pennsylvania State University; 1990.
- Zarit SH, Reeve KE, Bach-Peterson J. Relatives of the impaired elderly: Correlates of feelings of burden. *Gerontologist* 1980;20:649-55.
- Zarit S, Orr NK, Zarit JM. The Hidden Victims of Alzheimer's Disease: Families Under Stress. New York, USA: NYU Press; 1985.
- Rankin ED, Haut MW, Keefover RW, Franzen MD. The establishment of clinical cutoffs in measuring caregiver burden in dementia. *Gerontologist* 1994;34:828-32.
- Arbuckle JL. IBM SPSS Amos 22 User's Guide. Crawfordville, FL: Amos Development Corporation; 2013.
- El Bcheraoui C, Memish ZA, Tuffaha M, Daoud F, Robinson M, Jaber S, *et al.* Hypertension and its associated risk factors in the kingdom of Saudi Arabia, 2013: A national survey. *Int J Hypertens* 2014;2014:564679.
- El Bcheraoui C, Basulaiman M, Tuffaha M, Daoud F, Robinson M, Jaber S, *et al.* Status of the diabetes epidemic in the Kingdom of Saudi Arabia, 2013. *Int J Public Health* 2014;59:1011-21.
- Bauer M, Fitzgerald L, Haesler E, Manfrin M. Hospital discharge planning for frail older people and their family. Are we delivering best practice? A review of the evidence. *J Clin Nurs* 2009;18:2539-46.
- Tuithof M, ten Have M, van Dorsselaar S, de Graaf R. Emotional disorders among informal caregivers in the general population: Target groups for prevention. *BMC Psychiatry* 2015;15:23.
- Brulin C, Gerdle B, Granlund B, Höög J, Knutson A, Sundelin G. Physical and psychosocial work-related risk factors associated with musculoskeletal symptoms among home care personnel. *Scand J Caring Sci* 1998;12:104-10.
- Hofman CS, Makai P, Blom JW, Boter H, Buurman BM, Olde Rikkert MG, *et al.* Comparing the health state preferences of older persons, informal caregivers and healthcare professionals: A vignette study. *PLoS One* 2015;10:e0119197.