

Dementia and family burden of care in Lebanon

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The burden on and mental well-being of family carers for the elderly, especially those with dementia, has been well studied in high-income countries and to a lesser extent in the Arab region. Our study of Lebanese carers highlights the importance of considering the psychological well-being of the family carer, and the role of dementia and depression in increasing the burden of care. Psychosocial interventions have produced equivocal results and therefore customised and contextualised interventions need to be researched. Greater understanding of the coping mechanisms used by carers is required and an examination of the positive aspects of caring is warranted.

Background

There is an unprecedented growth of the global population aged 60 and over, which is expected to expand further, from 12% in 2014 to 21% in 2050. Most elderly individuals live in low- and middle-income countries (Bluestone *et al.*, 2015). With the increased survival of older people, morbidities become more prevalent. Often these morbidities, in particular dementia, are associated with disability. Consequently, the elderly require assistance and care at different levels: medical, psychosocial and financial (Ryan & Wroblewska, 2013). Up to 47 million people in the world are living with dementia today, and this number will double every 20 years (Prince *et al.*, 2015). Most people with dementia reside in low- and middle-income countries (Prince *et al.*, 2015).

Most care for the elderly is provided either by formal services or by the family. The former includes nursing home placement and is mainly practised in high-income countries. Family-based care is predominant in low- and middle-income countries, especially in the Arab region, where it is considered an obligation and a social tradition. Consequently, the level of use of institutionalisation is one-fifth of that in high-income countries (Sibai, 2009).

In the Arab region, only a handful of studies have been conducted on carers of the elderly (Leichtentritt *et al.*, 2004; Khalaila & Litwin, 2011). Studies on the impact upon the person doing the caring are scarce. None has examined the effect of dementia on the carer's well-being (Seoud *et al.*, 2007; Chemali *et al.*, 2008). Nevertheless, there has

been a call for action emphasising the importance of recognising the essential role of the family in low- and middle-income countries and how best to support them in that task (Sibai, 2009).

Lebanon is a small middle-income country in the East Mediterranean region where the proportion of people aged 60 years or over is projected to reach 26% in 2050 (Mirkin, 2010). Only 1.4% of the elderly live in nursing homes, and 70% are females (Chemali *et al.*, 2008). As in other countries in the Arab region, cultural and religious values emphasise the central role of family care. A recent study showed that a typical Lebanese family carer is a married daughter (average age 46 years), who is usually unemployed (67%) and is providing care to a 76-year-old widowed woman who lacks medical insurance (Seoud *et al.*, 2007). Reports in the literature show that the impact on the carer of looking after an elderly relative with cognitive impairment, behavioural problems or dementia leads to high rates of depressive disorders, anxiety, feelings of burden and poor physical health (Papastavrou *et al.*, 2007; Brodaty & Donkin, 2009; Tremont, 2011).

Empirical study

We conducted a cross-sectional study of people aged 65 years and over in Lebanon to determine the prevalence of dementia and factors associated with its development.

Method

Interviewers conducted home visits to collect demographic, socioeconomic and health-related data. Information on 64 identified carers was used in this study to evaluate the impact of caring for a dependent elderly person.

Caring was classified as hands-on care, or involved indirectly (organising care) or partially/slightly participating in direct care. Dementia and depression were assessed by the 10/66 Dementia Research Group (DRG) diagnostic assessment and the Geriatric Mental State (GMS) (Phung *et al.*, 2014). The burden of care was assessed using the Zarit Burden Interview (ZBI), which measures the strain associated with the care of individuals with dementia (Zarit *et al.*, 1985). The maximum possible score on this scale is 88, and scores were treated as continuous; a higher score reflected a higher burden and strain. We assessed the sociodemographic characteristics of the carer: age, gender, current marital status and current working status. Their relationship to the elderly person was categorised

as immediate family (husband/wife, or daughter/son) and non-immediate family (other relatives or friend); two further factors were co-residency and whether there was also a paid helper.

Results

Just over a third of the carers surveyed (36%) provided hands-on care. The other two-thirds were involved indirectly (organising care) or partially/slightly participating in direct care. The mean age of the carers was 48 (s.d. 16.4) years; their age was not statistically associated with burden of care (Spearman's rho correlation coefficient = 0.225, $P = 0.074$). They were mostly female (75%) and married (66%), and about half (55%) did not work outside the home. Slightly more than half (56%) were immediate family members of the elderly person (spouse, son or daughter).

The elderly subjects of care were almost all female (83%) and had an average age of 78 (s.d. 7.5) years (their age was not associated with burden of care – Spearman's rho correlation coefficient = 0.029, $P = 0.821$). One-quarter (23%) also had a paid helper. A large minority had dementia (30%) and 20% had depression.

As measured by the ZBI, strain was greatest among carers who provided hands-on care (Table 1). ZBI scores were higher if the elderly relative had dementia or depression, and among carers who

were females, immediate family members, unmarried, unemployed, co-residing with the elderly person or had a paid helper, as compared with their respective counterparts.

Just 8% of carers had a ZBI score above the level at which an *unduly* high level of burden can be assumed (Schreiner *et al*, 2006). These were women and mostly daughters (just one was the wife of the elderly person). They were older than other carers (mean age 58 years); all were co-residing with the elderly person and providing direct hands-on care, and most were caring for a relative with dementia.

The carers' profile in our sample did not differ significantly from that in earlier studies in Lebanon and elsewhere (Schreiner *et al*, 2006; Papastavrou *et al*, 2007), where it has been found that burden is greater for those managing someone with dementia (Brodaty & Donkin, 2009; Tremont, 2011; Ornstein & Gaugler, 2012). Interestingly, the presence of support provided by a paid helper, a common practice in the region, did not alleviate the burden on the family carers.

Discussion

In the care of an elderly person, the involvement of family members extends beyond providing immediate basic care and entails emotional involvement. That involvement can be very stressful when the person being cared for suffers from dementia or other mental health problems, such as depression. We propose that the Alzheimer's Association and similar non-governmental organisations in Lebanon could be involved in order to improve the management of persons with dementia and consequently to alleviate the burden placed upon family carers. We need greater understanding of the coping mechanisms that carers use and the different types of social support they are resorting to in order to help them experience their role as carers as a fulfilling and positive one. Previous studies of this subject have tended to emphasise the burden upon carers, the risk of burnout, and their poor mental and physical health. Few have addressed positive experiences of being a carer, and we need better to understand how such a stressful task might nevertheless be rewarding.

References

- Bluestone, K., Escribano, J., Horstead, K., *et al* (2015) *Facing the Facts: The Truth About Ageing and Development*. Age International.
- Brodaty, H. & Donkin, M. (2009) Family caregivers of people with dementia. *Dialogues in Clinical Neuroscience*, 11, 217–228.
- Chemali, Z., Chahine, L. M. & Sibai, A. M. (2008) Older adult care in Lebanon: towards stronger and sustainable reforms. *Eastern Mediterranean Health Journal*, 14, 1466–1476.
- Khalaila, R. & Litwin, H. (2011) Modernization and future care preferences: a cross-sectional survey of Arab Israeli caregivers. *Journal of Advanced Nursing*, 67, 1614–1624.
- Leichtentritt, R. D., Schwartz, V. & Rettig, K. D. (2004) The lived experiences of Israeli Arab Muslims who are caring for a relative with cognitive decline. *International Journal of Aging and Human Development*, 59, 363–389.
- Mirkin, B. (2010) *Population Levels, Trends and Policies in the Arab Region: Challenges and Opportunities*. United Nations Development Programme, Regional Bureau for Arab States.

Table 1

Comparison of mean scores for burden of care by carers' and elderly relatives' characteristics using non-parametric testing ($n = 64$)

		Burden of care (ZBI score)		
		Mean	s.d.	P
<i>Carer's characteristics</i>				
Gender	Male	3.44	3.59	0.863
	Female	6.94	11.70	
Relationship to elderly person	Immediate family	8.42	12.98	0.106
	Not immediate family	3.04	3.95	
Current marital status	Not married	9.05	14.28	0.140
	Married	4.50	7.30	
Current work status	Unemployed	8.57	13.41	0.759
	Employed	3.03	2.45	
Co-residency with elderly	No	3.16	3.34	0.422
	Yes	8.97	13.78	
Paid helper	No	4.96	8.25	0.451
	Yes	9.67	15.23	
Caring role	Organisational/partial	2.98	3.12	0.205
	Hands on	11.57	15.51	
<i>Characteristics of elderly relatives</i>				
Gender	Male	8.73	10.75	0.142
	Female	5.51	10.30	
Dementia	No	3.47	5.02	0.015
	Yes	12.21	16.06	
Depression	No	2.98	5.24	<0.001
	Yes	18.15	15.84	

ZBI, Zarit Burden Interview.

Ornstein, K. & Gaugler, J. E. (2012) The problem with 'problem behaviors': a systematic review of the association between individual patient behavioral and psychological symptoms and caregiver depression and burden within the dementia patient-caregiver dyad. *International Psychogeriatrics*, *24*, 1536–1552.

Papastavrou, E., Kalokerinou, A., Papacostas, S. S., et al (2007) Caring for a relative with dementia: family caregiver burden. *Journal of Advanced Nursing*, *58*, 446–457.

Phung, K. T., Chaaya, M., Waldemar, G., et al (2014) Validation of the 10/66 Dementia Research Group diagnostic assessment for dementia in Arabic: a study in Lebanon. *Journal of Geriatric Psychiatry and Neurology*, *27*, 282–290.

Prince, M., Wimo, A., Guerchet, M., et al (2015) *World Alzheimer Report 2015. The Global Impact of Dementia. An Analysis of Prevalence, Incidence, Cost and Trends*. Alzheimer's Disease International.

Ryan, P. & Wroblewska, A. (2013) Caring for older adults. In *Ageing and Older Adult Mental Health: Issues and Implications for Practice*, pp. 214–225. Routledge.

Schreiner, A. S., Morimoto, T., Arai, Y., et al (2006) Assessing family caregiver's mental health using a statistically derived cut-off score for the Zarit Burden Interview. *Aging and Mental Health*, *10*, 107–111.

Seoud, J., Nehme, C., Atallah, R., et al (2007) The health of family caregivers of older impaired persons in Lebanon: an interview survey. *International Journal of Nursing Studies*, *44*, 259–272.

Sibai, A. M. (2009) *Older People in Lebanon: Voices of the Caregivers*. Center for Studies on Aging. Available at http://www.csa.org.lb/cms/assets/csa%20publications/policy%20briefs%20pdfs/csa_policy_brief_issue1_voices_of_the_care_givers.pdf (accessed December 2016).

Tremont, G. (2011) Family caregiving in dementia. *Medicine and Health, Rhode Island*, *94*, 36–38.

Zarit, S., Orr, N. K. & Zarit, J. M. (1985) *The Hidden Victims of Alzheimer's Disease: Families Under Stress*. New York University Press.