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**Editorial:****Dementia Patient in the Family: Impact of Dementia Care on Family Caregivers****Rabab Atta Saudi<sup>1</sup>, Mosleh A. Ismail<sup>1</sup>**<sup>1</sup>MD Family Medicine, Faculty of Medicine, Suez Canal University

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Over the last decades; the main feature of the Egyptian population is a gradual increase in life expectancy for both genders. Egypt has the highest percentage of elderly among Arab world (7.2%), and this proportion is expected to increase to 9.9% in 2030 and 15.3% in 2050.<sup>(1)</sup> Such rapid increase in the elderly population would definitely pose a variety of challenges; such as inadequate pension, poverty, polypharmacy, and inadequate health insurance coverage.

With the rapidly aging population, family physician will be increasingly required to provide geriatric care and manage their chronic illnesses in the view of unavailability of geriatricians with adequate numbers.<sup>(2)</sup> Aging is associated with lowered cognitive and physical function. Dementia is the most common and the most severe cause of cognitive impairment and disability; it is the largest cause of dependency on others for performing activities of daily living (ADL) and the main factor that affects health related quality of life (HRQoL)

negatively.<sup>(3)</sup> It is estimated that 35.6 million people are currently living with dementia worldwide and that the number will nearly double every 20 years, reaching 115.4 million in 2050, with the majority living in developing countries. Consequently, the health and social burden of cognitive impairment and dementia will rise dramatically in these regions. Out of the total number of people with dementia worldwide, 57.7% lived in developing countries in 2010 and a proportionate increase to 70.5% by 2050 is anticipated.<sup>(4)</sup>

The care of people with dementia is complex and unpredictable along with it is physically, emotionally, and financially demanding. People with dementia become physically dependent and exhibit behavioral symptoms such as repetitive questioning, verbal or physical aggression, and resistance to care. The care of patients with dementia is shouldered primarily by their spouses, adult sons and daughters along with children-in-law. Approximately two-

thirds of these family caregivers are women. The majority of caregivers have not assessed regarding their abilities and resources to be caregivers. Also, they have not received a training to manage the multiple challenges facing them on providing care to elderly patients with dementia. The majority of caregivers do not perceive their health care providers to be adept at managing patient-related issues.<sup>(5)</sup>

In 2017, the Alzheimer's Association estimated that caregivers of people with dementia in the United States provided 18.4 billion hours of unpaid care annually, equating to a cost of \$232.1 billion. A caregiver is defined as someone who is unpaid in supporting a friend or family member with dementia who cannot manage without their assistance. These many hours of unpaid care protect society from a huge financial burden but possibly at considerable personal caregiver cost. Although some caregivers reported positive outcomes, many reported negative impacts on their quality of life (QoL).<sup>(6)</sup> Dementia is often considered to be a threat to an individual's well-being, whether that individual is the person who receives a dementia diagnosis or the

family member who provides the majority of informal dementia care. Multiple stressors and strains arising from the dementia context have been examined for their potential to threaten the well-being of either the person with dementia or caregiver within the family.<sup>(7)</sup>

### **Psychological Outcomes of Dementia on Family Caregivers:**

**Burden** is defined as the extent to which caregivers perceive that caregiving has had adverse effect on their emotional, social, financial, physical, and spiritual functioning. Burden occurred in higher rates among dementia family caregivers compared to non-caregivers with patient behavioral symptoms being one of the strongest predictors of burden. Other factors influencing burden include the patient's severity of dementia and their functional status. The type of dementia carries influence on burden. For example, frontotemporal dementia and dementia with Lewy body caregivers have higher ratings of burden compared to Alzheimer's disease (AD) caregivers. Male caregivers have lower ratings of burden compared to female caregivers. Caregiver variables such as competency, coping styles, and personality are other

strong predictors of burden.<sup>(5)</sup> In a study of spouse and adult child caregivers, the majority (83.9 %) endorsed high levels of burden. In this study, burden fell into three domains: the impact of dementia on the caregivers' life, guilty feeling and frustration/embarrassment. Younger caregivers reported higher burden than older-age spouse caregivers, and their burden had a more direct association with impact of dementia on their lives and feelings of guilt.<sup>(8)</sup>

**Guilt** has been identified as a common experience of caregivers. Guilt influences feelings of competence, burden, and distress regarding patient's behavioral symptoms. Caregivers may experience guilt over concerns that they have abandoned the patient to respite care and guilt that they could have done more to prevent placement.<sup>(5)</sup>

**Depression** is a significant psychological outcome of dementia caregiving that is highly predicted by the patient's neuropsychological symptoms, being female, and being a spouse caregiver.<sup>(15)</sup> Depression carries an important influence over other aspects of the caregiver experience. For example, depressed caregivers have higher ratings

of burden and suicidal ideation. In a study of suicidal ideation, one in six family caregivers endorsed suicidal thoughts more than once during the previous year. This rate was consistent across settings of care (home or long-term care) and among caregivers whose care recipient had passed away within the past 2 years.<sup>(9)</sup> Homicidal ideation among family caregivers of people with dementia; physical and verbal abuse of their care recipient was reported in previous research.<sup>(10)</sup>

#### **Physical Health Outcomes of Dementia on Family Caregivers:**

Caregiving role in general was associated with increased risk of morbidity and mortality. In addition, family caregivers rate their health as fair to poor.<sup>(6)</sup> Dementia family caregivers, compared to normal controls, have a higher incidence of obesity, cardiovascular disease, and hypertension was reported in previous research.<sup>(5)</sup>

Sleep disruption and sleep quality are affected by caregiving. Caregivers endorse multiple causes for poor sleep that include need to provide care and supervision during the night and the strain of caregiving.<sup>(8)</sup> Risk for Cognitive decline

and dementia are a concern for dementia caregivers. Caregivers have been shown to have worse cognitive abilities compared to non-caregivers. Cognitive skills were lower among caregiving spouses compared to non-caregivers and persisted even after the death of the spouse with dementia.<sup>11</sup>

Over 1000 dementia caregivers were followed over a 12-year period and had a six-fold increase in dementia risk after adjusting for age, education, Socio-economic status, and Apolipoprotein E (APOE) genotype. Husband caregivers had a slightly higher risk.<sup>12</sup> Researchers hypothesize that the chronic stresses of caregiving and the diminished richness of the cognitive and social environment perhaps may play a role.

#### **Assessing unmet needs of caregivers for people with dementia:**

Dementia caregivers often report unmet needs, burden, and health impairments. Optimal support for family dementia caregivers will likely benefit from better understanding and assessment of the prevalence and types of caregivers' unmet needs and associated socio-demographic and clinical characteristics. Previous evidence revealed that family

dementia caregivers reported high levels of physical, psychological, emotional, and social burden as well as health impairments. In addition, caregivers' burden and health impairments are associated with worse outcomes for people with dementia including behavioral and psychiatric symptoms, early institutionalization, low quality of life, and higher mortality.<sup>(13)</sup> Furthermore, previous studies indicate that caregivers of dementia patients demonstrate higher levels of unmet needs as well as lower levels of service utilization and lower identification rates of unmet needs by professionals compared to caregivers of patients with other chronic illnesses in the family. Such unmet need might hamper dementia caregivers' physical and mental health.<sup>14</sup> One third of caregivers with serious mental disorders was overlooked by physicians. Consequently, neither had they access to professional help nor were they advised to seek professional help for their condition.<sup>(15)</sup>

People with dementia prefer to remain in their familiar environment as long as possible. At the same time, health policy supports community-dwelling of people with dementia due to lower health

care costs. Therefore, one may expect that the social and economic value of family dementia caregiving will increase considerably in the future. However, in order to fulfill their role, caregivers must have access to support fitting their needs. This requires comprehensive assessment of caregivers' unmet needs.<sup>(16)</sup>

### References:

1. World Population Ageing Report. United Nations, New York. Department of Economic and Social Affairs. Population Division. 2015. Available at: <http://www.UN.com>.
2. Bussolo M, Koettl J, Sinnott E. Golden aging: prospects for healthy, active and prosperous aging in Europe and Central Asia. *Innov Aging*. 2017; 1(Suppl 1):1271. Published 2017 Jun 30. doi:10.1093/geroni/igx004.4631
3. Andersen CK, Wittrup-Jensen KU, Lolk A, et al. Ability to perform activities of daily living is the main factor affecting quality of life in patients with dementia. *Health Qual Life Outcomes*. 2004; 2:52. Published 2004 Sep 21. doi:10.1186/1477-7525-2-52
4. World Health Organization . Dementia: a public health priority. World Health Organization. 2012. <https://apps.who.int/iris/handle/10665/75263>
5. Merrilees J. The Impact of Dementia on Family Caregivers: What Is Research Teaching Us?. *Curr Neurol Neurosci Rep*. 2016;16(10):88. doi:10.1007/s11910-016-0692-z
6. Alzheimer's Association .Alzheimer's disease facts and figures. *Alzheimers & Dementia*. 2018.14, 367-425. doi:10.1016/j.jalz.2018.02.001 Crossref
7. Cunningham NA, Cunningham TR, Roberston JM. Understanding and Measuring the Wellbeing of Carers of People with Dementia. *Gerontologist*. 2019; 59(5):e552-e564. doi:10.1093/geront/gny018
8. Springate BA, Tremont G. Dimensions of caregiver burden in dementia: impact of demographic, mood, and care recipient variables. *Am J Geriatr Psychiatry*. 2014; 22(3):294-300. doi:10.1016/j.jagp.2012.09.006
9. O'Dwyer ST, Moyle W, Zimmer-Gembeck M, et al. Suicidal ideation in family carers of people with dementia. *Aging Ment Health*. 2016; 20(2):222-230. doi:10.1080/13607863.2015.1063109

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10. O'Dwyer ST, Moyle W, Taylor T, et al. Homicidal ideation in family carers of people with dementia. *Aging Ment Health*. 2016;20(11):1174-1181. doi:10.1080/13607863.2015.1065793
11. Borsje P, Hems MA, Lucassen PL, et al. Psychological distress in informal caregivers of patients with dementia in primary care: course and determinants. *Fam Pract*. 2016; 33(4):374-381. doi:10.1093/fampra/cmw009
12. Norton MC, Smith KR, Østbye T, et al. Greater risk of dementia when spouse has dementia? The Cache County study. *J Am Geriatr Soc*. 2010;58(5):895-900. doi:10.1111/j.1532-5415.2010.02806.x
13. Van der Lee J, Bakker TJ, et al. Multivariate models of subjective caregiver burden in dementia: a systematic review. *Ageing Res Rev*. 2014; 15:76-93. doi:10.1016/j.arr.2014.03.003
14. Stirling C, Andrews S, Croft T, et al. Measuring dementia carers' unmet need for services--an exploratory mixed method study. *BMC Health Serv Res*. 2010; 10:122. Published 2010 May 13. doi:10.1186/1472-6963-10-122
15. Riedel O, Klotsche J, Wittchen HU. Overlooking Informal Dementia Caregivers' Burden. *Res Gerontol Nurs*. 2016;9(4):167-174. doi:10.3928/19404921-20160531-02
16. Zwingmann I, Michalowsky B, Esser A, et al. Identifying Unmet Needs of Family Dementia Caregivers: Results of the Baseline Assessment of a Cluster-Randomized Controlled Intervention Trial. *J Alzheimers Dis*. 2019; 67(2):527-539. doi:10.3233/JAD-180244
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