

The aging caregiver in the aged world of dementia

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Old age population is growing worldwide at an impressive rate. Today, 8.5 percent of people (around 617 million) are aged 65 and over. This percentage is projected to increase to nearly 17 percent of the world's population by 2050 (1.6 billion) [1]. Population ageing is undoubtedly a demographic success, driven by changes in fertility and mortality due to economic and social development and to scientific progresses able to guarantee a better health for a larger number of people. However, as people live longer, chronic diseases become more prevalent, with a significant impact on health and care systems, particularly when they have been structured and built mainly for treating acute illnesses and young subjects. Therefore, although the "hospital centered" system is still the prevalent one, it is no longer the most suitable. But changing minds is a hard job. Although chronic diseases are increasing, both public and private health systems are in trouble when they have to manage these new needs. This is particularly evident in caring people with dementia, a disease that has become a leading cause of death and of increasing burden for society, family and elderly themselves. In 2016 an estimated 5.4 million Americans of all ages suffer from Alzheimer's disease (AD) and 81% of them age 75 years or more [2]. Considering that several people with dementia remain undiagnosed, this percentage is probably much higher. It seems that becoming "demented" is the pledge that developed countries has to pay to live longer. A large scientific literature can be found on dementia pathogenesis, drug discovery or implications on health care systems. On the contrary, the impact that diagnosis has on personal and social aspects, quality of life and community engagement of people living with such a cruel disease and their family is less considered and less taken on responsibility by the health system. When a person begins to experience the symptoms of dementia, the family often starts to take an unexpected, long and difficult journey of its own, experiencing the loneliness of living with dementia, without supports. Moreover, in an old-age country such as Italy where, whether for traditional family connections or for economic difficulties that reduces the possibility to afford the costs of a nursing home, people with dementia are mostly cared at home, by families. So, family members must become 'caregivers', often without a choice, and have to try and cope with the emotional impact and implications of such a disease and consequences on their lives [3-5]. They have to face, understand and manage the changes they see, day by day, in their relative, provide emotional and practical help, and make difficult decisions about treatment options, use of services, finances, and long-term care. Thus, they also become "patient" (the person who suffers, in Latin), who needs support and assistance. Caregiving of dementia carries high financial, social, and emotional price. What is a new and unknown experience, in the aged world of dementia, is that caregivers aged too. Thus, it is not unusual to get into social contexts where a disabled old daughter must take care of a centenarian mother with dementia. For this reason, home care

arrangements are often critical and situations become unmanageable. Looking into data from the ReGAI project (Rete Geriatrica Alzheimer-Geriatric Network on Alzheimer's disease) -a large longitudinal Italian multicentric clinical-based study, promoted by the Italian Society of Gerontology and Geriatrics- from 2001 to 2005 we collected data from 544 caregivers of elderly subjects with dementia and found that their mean age was 56 years. Of them, 12% aged over 75 years. What happened just after ten years? Looking into data of the 2017 cohort, the mean age of 187 caregivers raised to 58 years and 15% were over 75 (unpublished data) and these percentages are projected to increase. Thus, if the caregiver remains healthy, then the quality of life of the care recipient will be better. Conversely, a failure in caregiver health may collapse this fragile support system. Family caregivers are essential to guarantee the quality of life of people with dementia, for whom home is the best and preferred care setting. In this context, home remains the safer place where family members can take care of such a frail and needy person. In the aged world of dementia, the aged caregiver is becoming inefficient in this hard task, but this emerging problem is still underestimated in our society and very few seem to pay attention to this collateral issue. Italy is currently one of the European countries with the highest proportion of old people, and this group, in turn, includes a large number of caregivers. Thus, a novel strategy is urgently needed for promoting and improving interventions in the field of dementia, not limited to therapeutic actions, but focusing also on the support of patients and their aged relatives throughout a well-established and financially supported pathways of care. Creation of integrated networks of services to improve care and quality of life of persons with dementia and their families must have the highest priority in our health systems.

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Conflicts of interest

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