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COMMENTARY

Carers' distress

Older individuals prefer to continue living in their own homes maintaining their familiar environment keeping their social relations and living habits, instead of threat of loss of autonomy and independence through transition to nursing home (NH), especially if they are in need of care and belong to the oldest-age group. Fewer than half of NH residents reported having a good quality of life. Abuse of elder people in NHs is still a serious problem and most of the affected persons are afraid of being admitted to a NH (Cooper *et al.*, 2008; May *et al.*, 2019). By an arrangement of formal or informal home care or a combination of both, affected persons and their relatives increasingly successfully prevent or delay nursing home placement (NHP), so that over the past decades the social structure of the group of NH residents has been changed: mean age at entry has increased, the length of residence has shortened, and a substantial increase in need of care can be observed before transition to a NH (Schneekloth and Wahl, 2007). An admission can often no longer be prevented, if (a) no potential caregiver is available – mostly in case of widowhood, and if no other relative of the second or third generation is attainable; (b) when the necessary caregiving time and effort exceed the capabilities of the informal caregiver, that is, in case of severe impairment of cognitive or functional status, or a disease in its terminal phase which require 24/7 care; or (c) if the adjustment to a serious adverse event such as the death of the spouse or the recovery from a severe disease does not succeed sufficiently (Luppa *et al.*, 2012a). Rephrasing, if a person in need of care suffers from severe mental, cognitive, and/or functional impairment, the likelihood of a transition to a NH increases significantly if an adequate support or an appropriate assistance in the requirements of daily living is neither available nor organizable (Luppa *et al.*, 2012b).

In this regard, dementia has been shown as the main cause for institutionalization in the elderly (Aguero-Torres *et al.*, 2001). Currently, there are about 50 million people with dementia in the world, with 10 million new cases of dementia every year (World Health Organization, 2017). The total number of people with dementia is projected to reach 82 million in 2030 and 152 million in 2050 (World Health Organization, 2017). The majority of them are cared for by relatives in the community (World Health Organization, 2012). It has been shown that these family carers that care for individuals with dementia perceive significant higher distress than caregivers that care for individuals without dementia developing more depressive symptoms and physical problems (Pinquart *et al.*, 2003). And caregivers who are heavily burdened may opt for a transition to a NH of the person in need of care as a "role exit" (Gaugler *et al.*, 2011).

Terum *et al.* (2021), in this issue of *International Psychogeriatrics*, examine within the Dementia Study of Western Norway (DemVest) study specific aspects of carer distress that may influence time until nursing home admission (NHA) of individuals with mild Alzheimer's disease and dementia with Lewy bodies. In a previous study, the authors showed that a higher score on the Relative Stress Scale (RSS) predicted a faster admission to NH (Svendsboe *et al.*, 2018). Therefore, the aim of their present study was to assess individual items of the RSS for looking beyond the sum score of the RSS and special factors in experiencing distress in the role of a caregiver.

In the past two decades, research literature reported carers burden and distress both as consistent and significant factors influencing NHP (Cepiou-Martin *et al.*, 2016; Gaugler *et al.*, 2008; Luppa *et al.*, 2008; Toot *et al.*, 2017). The construct "caregivers burden" has been considered as multidimensional response to physical, psychological, emotional, social, and financial (named primary) stressors associated with the caregiver's experience. These primary stressors represent the objective characteristics of the caregiving situation, such as caregiving daily hours, duration of the caregiving, and caregiver's health. And the experience of burden is mediated by other factors besides the primary stressors, particularly the caregiver's resources such as personal and social resources as well as community-based care available. Caregiver's burden means – as secondary stressor – the subjective appraisal of the objective caregiving stressors. Terum *et al.* (2021) found that the factor carer's distress measured with the 15-item Norwegian RSS is an important contributor to the time of NHA: in this study, 19.3% of the total variance of time until NHA was explained by that factor. In detail, the following items of the RSS were shown as significant predictors of shorter time to NHP: feeling of

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frustration and of limitations in social life, not being able to get away on holidays and the feeling of being unable to cope with that situation. The feeling of frustration was reported to be one of the negative feelings besides impatience, resentment, and disappointment. However, higher importance is the handling and channeling of such negative feeling, which in turn leads to a higher carers burden (Terum *et al.*, 2021). Limitations in social life and not being able to get away on holidays can be summarized under the need to be free from the care responsibilities from time to time. Toot *et al.* (2017) reported in a meta-analysis a significant increased risk of carers burden for NHP of 7% (Hazard ratio [HR] 1.07, 95% CI 1.03–1.11). Role captivity as special aspect of carers burden was found to be a significant factor (HR 1.14) in another study, while "role overload" as well as "worry/strain" were insignificant (Gaugler *et al.*, 2000) which corresponds to the findings of Terum *et al.* (2021).

The decision to admit a person in need of care can be seen as a complex, multifactorial process and is based on patient and caregivers as well as environmental conditions (Ducharme *et al.*, 2012, Luppa *et al.*, 2008). An in-depth examination of these factors strongly associated with the final decision to quit the caregivers "job" and change the life of the person in need of care considerably and often non-reversibly facilitates the development and application of health and social strategies, of flexible and tailored interventions for the caregiver and/or the caregiving situation to delay the transition or at least assure a well-timed and well-organized transition. Because, often the person in need of care and their relatives experience high difficulties adjusting to the new caring situation in a NH (Sury *et al.* 2013).

For this purpose, Terum *et al.* contribute an important component to the research literature related to the investigation of the circumstances of institutionalization, because detailed information on factors affecting risk of NHP is relevant to enrich knowledge about the multidimensional, complex decision-making process and to develop effective interventions to prevent or delay NHP by supporting the carers with information, knowledge as well as financial, instrumental, and emotional assistance. A recent systematic umbrella review summarized studies examining interventions, such as caregiver support, respite care and adult day programs, case management, and preventive home visits (Duan-Porter *et al.*, 2020). However, their results indicated no benefit or inconsistent effects of home- and community-based care in preventing or delaying NHP. But they reported that higher intense interventions seem to have the potential to reduce the risk of NHP. Well-designed, clearly structured multicomponent interventions including both an educational and a therapeutic component offering also a support group for the carers (e.g. Dickinson *et al.*, 2017) could help maintain the mental and somatic health of the caregivers and reduce the experienced burden. Furthermore, the involvement of the carers in influencing health care decisions and planning interventions could be a further promising approach.

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