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The Epidemiological Approach to Disability: The Specific Burden of Dementia

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The ageing of the population

The ageing of the baby-boom generations and the continuous increase in life expectancy are two combined phenomena which lead to an increase in both the number and the proportion of elderly people. According to projections for France, one person out of three will be aged 60 years and over in 2050, and the group of 75 years and older would increase from 4.9 millions to 10.9 millions (i.e. +120 per cent), and the group of the oldest-old, the 85 years and more, would grow from 1.1 to 4.2 millions (i.e. +280 per cent). In that context, the worry of an explosion of the burden on society raises, especially due to disability and loss of autonomy associated with ageing and age-related pathologies. Indeed, we live longer, but what are the consequences of this increasing life expectancy in terms of quality of the years won? Do we live older but in more and more deteriorated conditions? Does medical progress allow to keep frail people alive, individuals who before did not survive from conditions such as cancer or stroke? Are we going to face an explosion of the age-related pathologies, such as Alzheimer's disease? Or on the contrary, can we expect to live longer and with a postponement of the deterioration of health to older ages? In the demographic and economic current context, these questions are of particular interest. At an individual level, an increasing life is good news, provided that the years won are lived in good conditions, with dignity and a preserved quality of life. At a collective level, several difficulties will have to be faced and in a relatively near future: the financing of the old age pensions, the increasing health costs, the growing needs of disability care…

Does the increasing life expectancy necessarily mean an explosion of disability?

The epidemiology of disability conducted over the last four decades, mainly in the U.S., but not exclusively, provided interesting findings on the evolution of disability over time. At the end of the 1970s, the prevalence of some diseases significantly progressed in the elderly population (such as diabetes and circulatory diseases), leading to an increase in the prevalence of disability. Then, since the 1980s a trend has reversed and never stopped (excepted in a very recently publication, an increased prevalence of disability is observed in the U.S., in the younger generation of elderly (60-69 years), mainly explained by the impact of the epidemic of obesity1). Excepted this publication, the international literature published in the last decades would suggest a postponement of the “entry in oldness” to older ages with multifactorial explanations: medical progress, efficiency of prevention, increasing level of education, significant improvement of life and work conditions, technological progress to compensate deficiencies and societal evolution of the representation of ageing. For France, in the Paquid study, a French epidemiological cohort on cerebral and functional ageing, a significant functional improvement was observed in the 1990s by comparing the prevalence of disability between two generations of elderly of the same age (75 to 84 years old), ten years apart in 1988 and in 1998. The proportion of subjects fully independent in daily activities increased by 73 per cent in ten years, from 14 per cent to 25 per cent.[2] These results confirmed the trend towards decline mainly observed in most industrialised countries.[3] These findings would confirm the empirical observations, that a 65-year-old women is not considered as old in 2010, whereas she was three or four decades ago.

However, regarding the demographic evolution and even if the favourable trend of functional improvement continues in the future, modern societies will probably face an increase in the number of elderly people living with disability and loss of autonomy.

The burden of dementia

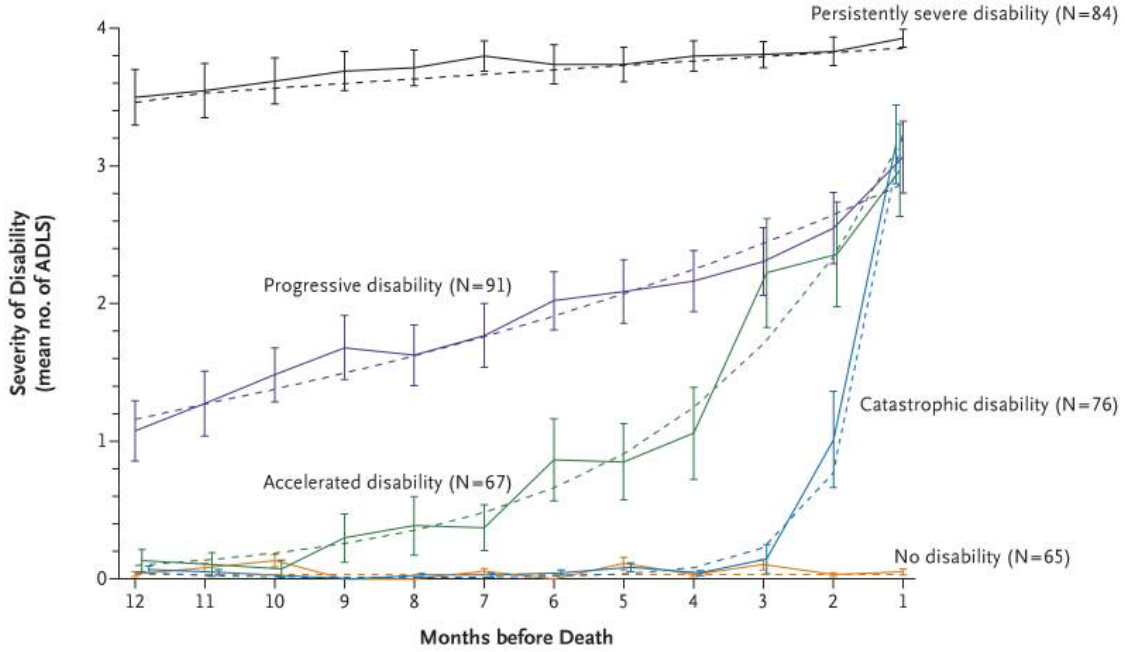
The disablement process is highly multifactorial and a lot of pathologies have been identified as disabling, such as stroke, diabetes, arthritis, depression or sensory impairments.[4-5] However among them, cognitive decline and dementia represent, by far, one of the major determinants of the process in the elderly.[5-6] How can one explain the huge contribution of dementia to disability and loss of autonomy? Three main explanations can be propounded. The first one is the high levels of prevalence and incidence of the disease in the elderly population. According to the Paquid cohort (the first main epidemiological cohort on dementia in France), 18 per cent of the people aged 75 years and older suffer from dementia.[7] Once extrapolated to the total French population, around 855,000 persons lived with dementia in 2005, with an annual incidence of 225,000 new cases per year.[8] The projections based on the hypothesis of a constant level of mortality and in the same conditions of treatment (i.e. in absence of curative treatment), suggest that France will be faced with 1.3 million cases of dementia in 2020, and more than 2 million in 2040. Regarding worldwide figures, the projections are impressive. According to Brookmeyer *et al.,*[9] one person out of 85 in the world will live with dementia in 2050 (i.e. around 106.2 millions of cases) and 43 per cent of them will need a high level of care. The second explanation of such a burden in terms of disability is that the period of time lived with the disease is higher than in many other age-related pathologies, more rapidly lethal at a severe disabling level, such as stroke, cancers or cardio-vascular diseases. The final explanation is the devastating consequences of the disease on autonomy in daily life, as presented in detail below.

Dementia is characterised by a progressive loss of cognitive capacities (memory, judgment, abstract thinking, attention…) and of functional abilities. Significant repercussions in daily living are moreover one of the diagnostic criteria for dementia according to the DSM-IV (Diagnostic and Statistical Manual of Mental Disorders). Consequently, each case of dementia at the diagnosable level is necessarily restricted in their capacities to function in daily life. Contrary to several age-related pathologies, dementia is characterised by its progressive and irremediable evolution, leading to a total loss of autonomy in each activity of daily life. At the beginning of the dementia process, the patients are mildly restricted, especially in the most cognitively demanding tasks, such as handling finances. But the need for assistance increases with the progression of the disease and at the end of the pathological process, the individuals suffering from dementia need total assistance for each task, even for the very basic ones, such as dressing, bathing or even feeding. According to the Paquid cohort (in participants aged 75 years and older), the prevalence of disability in basic ADL is 23 per cent in mild dementia and reaches 98 per cent in the very severe stage of the disease.[7] At this stage, the burden in daily life for family caregivers often leads to the exhaustion of the next-of-kin and to the placement of the patient in a long-term care institution. According to Helmer *et al.,* 39 per cent of people with dementia lived in institution, versus only 3.3 per cent for people without dementia,[7] and people with dementia would account for 72 per cent of the institutionalised residents. Globally, 57 per cent of the subjects living with dementia needed assistance to perform basic ADL (versus only 4 per cent of the non-demented people). Dressing and bathing are the two first tasks which hierarchically first require help in the course of dementia. Noted that the demented cases accounted for 74 per cent of the whole ADL-disabled subjects and for 88 per cent of the most severely disabled individuals *(defined by a need for help in at least three of the four following ADL: bathing, dressing, transferring and feeding).*[7]

Finally, the burden of dementia in terms of disability was confirmed in a recent publication on the course of disability in the last year of life.[10] The study was conducted among 383 decedents, initially aged 70 years old and over and based on monthly telephone interviews. The authors identified five main trajectories of disability in basic ADL, which are presented in figure 1. More than half of the subjects were in the three less severe trajectories of disability before death: 17 per cent of the subjects had no ADL disability at all before death, 20 per cent presented catastrophic disability (i.e. with no disability three months before death) and 17 per cent had accelerated disability (i.e. without severe disability six months before death). Around 22 per cent had persistently severe disability. When the authors explored the conditions leading to death, they observed a high heterogeneity in disability trajectories, excepted for subjects who died from advanced dementia (68 per cent of them having a persistently severe disability

trajectory) and from sudden death (half of them having no disability before death). The authors conclude that in most of the decedents, the course of disability in the last year of life does not follow a predictable pattern based on the condition leading to death, except for people suffering from dementia mainly characterised by a persistently severe disability.

Figure 1: Trajectories of disability in the last year of life among 383 decedents



Source: Gill TM, *et al.* (2010), *N Engl J Med* 362, 1173-1180.

Conclusion

To conclude, the epidemiology of disability provides some optimistic findings for trends in ageing with a significant functional improvement across generations of elderly people over the three last decades. The studies suggested a postponed onset of disability to older ages. However, regarding the demographic evolution of the population, these favourable trends will probably not compensate the ageing of the population and the associated increased needs of disability care. Most of the modern societies will probably have to face an increase in the number of disabled elderly people, and consequently an augmentation of the needs for disability care and of the associated increased costs. Among all the disabling pathologies, Alzheimer's disease and related disorders represent one of the major determinants of disability. In absence of curative treatment (only symptomatic treatments are currently available), with only few identified risk factors amenable to prevention, and regarding the major burden of dementia in terms of disability and loss of autonomy, the looming epidemic of dementia as populations age represents a huge challenge for all industrialised societies.

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